SUMMARY

A STUDY OF CARE PRACTICES FOR PERSONS WITH DEMENTIA IN ONTARIO'S HOMES FOR THE AGED

1.0 INTRODUCTION

1.1 Purpose of the Study

In 1989, the Elderly Services Branch of Ontario's Ministry of Community and Social Services initiated a comprehensive study of care practices for residents with moderate or severe dementia in Ontario's Homes for the Aged. The terms of reference for the study identified two objectives:

- to describe and compare the range of strategies and techniques used for managing residents with dementia in Ontario's Homes for the Aged; and
- to describe, as a special focus, the role of the special care unit in caring for the elderly with dementia, the unique features of the special care unit, and the experiences in using special care units in Ontario's Homes for the Aged.

In order to meet these objectives, the Flett Consulting Group Inc. and Social Data Research Ltd. surveyed all 181 Homes for the Aged in Ontario concerning care practices in general and care practices on special care units. The literature on care practices for elderly persons with dementia was also reviewed. The results of the study are available in three volumes from:

Residential Services Branch
Community Health and Support Services Division
Ontario Ministry of Community and Social Services
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2.0 LITERATURE REVIEW

2.1 Prevalence of Mental Disorders

Four studies of the prevalence of mental disorders among residents of long-term care facilities estimated prevalence in a range of 52% to 94% of residents. A fifth study estimated that 22% of institutionalized elderly persons in Ontario had severe disorientation.

2.2 Care Practices for Residents with Dementia

The special needs of residents with dementia arise from the symptoms of their disorder and their interactions with other persons. Their special care needs are related to problem behaviours, competency to make decisions, functional deficits, psychotic symptoms such as hallucinations, and suffering related to depression and anxiety. In other respects, the needs of residents with dementia are the same as those of other frail, elderly residents and are met through best practices of care. Good care practice is based on comprehensive assessment and reevaluation by an interdisciplinary care team, development of a care plan based on all assessment findings, and conscientious execution of the care plan.

2.3 Environmental Design for Residents with Dementia

Environmental design features important to all elderly include those intended to support decreased physical abilities and support good care practices. Features relevant to the elderly with dementia are features responding to wandering or pacing, loss of judgment, and other manifestations of the illness. Good environmental design follows these precepts: creation of a homelike environment; support to compensate for residents' diminished capabilities; avoidance of misleading cues about the environment, such as brick-patterned wallpaper; calm and quiet; clearly differentiated spaces; and a focus on residents' health and safety.

2.4 Special Care Units

Special care units (SCUs) are defined in the literature as separate units featuring supportive design for residents with dementia, with specialized programs and trained staff. In practice, units for residents with dementia vary considerably and the term "special care" may simply indicate some variation from the facility's standard practice.

This variability has made it difficult to assess the effectiveness of SCUs, and recent reviews of the literature have found no consistent research data on the benefits or disadvantages of these units. Some special care programs report initial improvements in terms of increases in socially appropriate behaviour and decreases in extreme behaviour among residents, with less precipitous decline thereafter. Programs fail to find consistent improvement in areas that are likely impaired by dementia, such as language skills, motor skills, and memory.

The size of SCUs usually is determined by available space and budgets, rather than by theoretical considerations about optimal size. While units of fewer than 20 beds were viewed as optimal, in practice units typically ranged in size between 20 beds and 34 beds.

No generally accepted criteria have been developed for admission to SCUs, although many accept only residents with irreversible dementia and problem behaviours and who have the ability to benefit from the program. In some facilities, residents remain in the SCU as their dementia progresses and care needs increase, while in others, residents are discharged when for physical, cognitive or behavioral reasons they no longer benefit from the program.

The ratio of direct care staff to residents (day shift) in three surveys of SCUs ranged from between 1:3 and 1:4 to between 1:7 and 1:12, Some units modify traditional assignments of tasks and others employ extra staff in the late afternoon and evening. Provision of training varies considerably.

Environmental design features also vary. These modifications, along with staff education and specialized therapy, are the chief cost components of special care.

Many facilities lack the resources to establish special units and instead find ways of improving the quality of care to all residents within limited budgets. Examples from the literature include restructuring of staff management and program schedules, creation of in-house day programs, and modest environmental adaptations.

3.0 SURVEY OF HOMES FOR THE AGED

A mail-out survey of all 181 Homes for the Aged in Ontario was conducted in the summer of 1990 to obtain information on residents' characteristics and a description of policies and care practices pertaining to residents with dementia living on general units of the Home. All Homes were also asked whether they had a separate unit providing care for residents with dementia and if so, to complete a second questionnaire concerning the profile of residents and care practices there.

A total of 133 completed returns were received, yielding a response rate of 80% (133/166), adjusting the sample base to remove 15 Homes that did not admit residents with dementia. Completed questionnaires concerning special care units were received from 67 Homes. Two Homes had two special care units and one had three units, resulting in a total of 71 responses.

The number of residents in each Home varied; 37.4% had fewer than 100 residents, 37.4% had 100 to 199 residents, and 25.1% had 200 residents or more.

Most of the discussion that follows focuses on special care units, with comparisons made to general practices with residents with moderate or severe dementia where differences were observed.

3.1 Age, Location and Size of Special Care Units

Special care units have a long tradition in Ontario's Homes for the Aged. While 40% of the Homes with such units indicated they were established within the last 10 years, another 44% indicated the units had been established before 1970.

Most units (67.1%) are located on the ground level. The number of residents living on each unit varied. While 9.8% reported fewer than 20 residents on each unit, 28.2% reported between 20 and 29 residents, 26.8% reported 30 to 39 residents, and 35.2% reported 40 or more residents.

3.2 Description of Residents

The Homes were asked to provide profiles of three groups of residents: all residents of the Home, residents with moderate or severe dementia (not living in a special care unit), and residents of special care units. Most residents of the Homes were female (72.0%) and most were single (86.2%). Half were 85 years of age or older (49.4%) and half (50.3%) required staff help with three or more activities of daily living. About one-third (38.2%) were independently mobile without a cane or walker, while the others were independently mobile with a cane or walker (22.0%), in a wheelchair (15.6%), or mobile only with staff assistance (24.2%).
Using definitions provided by the researchers, 66.6% of all residents in the Homes were judged by staff as having some form of dementia. While only 17.5% of residents had an actual diagnosis of Alzheimer's disease or related dementia on their chart, 40.8% were perceived to have moderate or severe forms of dementia.

Few differences were observed between all residents and residents with moderate or severe dementia (not living on a special care unit) in terms of age, sex, and marital status. However, residents with moderate or severe dementia (not living on a special care unit) required more help with activities of daily living, with 97.1% requiring help with three or more of these activities compared with 50.3% of all Home residents. Residents with moderate or severe dementia also required more help with ambulation, with 43.5% requiring staff assistance compared with 24.2% of all Home residents.

Residents of SCUs were younger than the residents of the Homes in general, with 31.8% aged 85 years or older compared with 49.4% of all residents. Most SCU residents (93.5%) were assessed as having moderate or severe dementia and 83.5% required assistance with three or more activities of daily living. SCU residents were more mobile than residents of the Homes in general, with 63.3% independently mobile without a cane or walker compared with 38.2% of all residents.

There were no differences between residents with moderate or severe dementia living on and outside of SCUs in terms of wandering, agitation, and incontinence. Thirty per cent of each group wandered; 48% of each group were agitated; and 68.8% of SCU residents were incontinent compared with 61.9% of residents with moderate or severe dementia outside the SCU. However, residents of SCUs were far more likely to be abusive or aggressive (69.9% vs. 29.4%) and to display hoarding or rummaging behaviours (74.1% vs. 17.5%).

3.3 Admission and Discharge Policies

Criteria for admission to SCUs that were reported frequently include danger to self, often because of wandering (85.7%); presence of unmanageable behaviour (84.1%); and diagnosis of irreversible dementia (74.3%). SCUs were more likely to use structured or formal assessment tools to assist with assessments of residents with moderate or severe dementia, compared with general practice in the Homes for such residents. The Folstein Mini-Mental State Examination was the most frequently cited instrument.

The most frequently cited reasons for discharge (other than death) for residents with moderate or severe dementia were the same for both the SCUs and the Home in general: resident requires specialized psychiatric care, resident displays violent behaviour, and resident requires more care than the unit can provide.

Registered Nursing Assistants (RNA) staff were more likely to be involved in on-unit admission assessments and transfer and discharge decisions on SCUs than they were in the Homes in general.

3.4 Care Planning

Most SCUs (95.7%) reported conducting more than one reassessment annually and 82.1% conducted no more than four reassessments annually. While two-thirds of the units (64.8%) indicated their residents are assessed as frequently as residents with moderate or severe dementia living elsewhere in the Home, one-third (33.8%) indicated their residents are reassessed more frequently than other residents, usually to monitor and address problem behaviour. Families are more likely to be involved in reassessments on SCUs than in the Home generally, with 62.3% of SCUs indicating that families are usually involved compared with 50.4% of respondents to the survey of general care practices.

Most SCUs (81.7%) indicated care plans were reviewed as frequently on the unit as elsewhere in the Home. Plans are reviewed each month in half the units (50.7%) and about once a year in the others.

3.5 Environmental Modifications and Technological Aids

SCUs were more likely than other units in the Homes to adopt measures to increase security on the unit. They were more likely to report alarming, coding or securing of exits (100% vs. 83.1%); securing outside areas used by residents (71.0% vs. 52.2%); securing adjacent elevator openings (45.8% vs. 36.5%); and using wide-angle mirrors on the unit (20.6% vs. 10.4%). Few Homes reported using video cameras.

The SCUs were also more likely to have adopted other safety and security measures such as door locks with key or combination (83.8% vs. 48.3%), identification bracelets (64.2% vs. 55.8%), controlled access or key to elevators (40.7% vs. 16.6%), electronic sensors on doors (39.4% vs. 35.6%), and electronic sensors on elevators (5.2% vs. 12.0%).

Most SCUs and other units in the Homes employed materials such as signs marking residents' doors to orient residents to time and place. Few differences were observed between units, although SCUs were more likely to have removed misleading stimuli such as art work.

SCUs were more likely than other units to have tried to accommodate wandering and reduce jostling among residents with moderate or severe dementia. The SCUs were more likely to report creation of space outdoors for wandering (82.9% vs. 43.9%), creation of spaces indoors for wandering (72.5% vs. 33.3%), and increased square footage for lounges ((48.5% vs. 25.7%).

The SCUs were also somewhat more likely to report measures to control noise--planned use of background music (49.3% vs. 38.6%), elimination of an intercom or public address system (31.4% vs. 28.1%). However, units outside the SCU were more likely to have carpeting or sound-absorbing finishes (40.0% vs. 29.6%).

Most SCUs and other units in the Homes have tried to compensate for residents' sensory deficits through various means, with 50% to 60% of both types of units indicating increased lighting, measures to reduce glare on floors, textured finishes, and even lighting levels. SCUs were more likely to report use of contrast to show where differences occur (ie., between doors and door knobs, dishes and tables, floors and walls), with 81.4% reporting use of this approach compared with 74.8% of the Homes generally. SCUs were also more likely to try to eliminate contrast where none occurred (ie., patterns on floors or changes in floor surfacing).

SCUs and other units in the Homes were equally likely to report use of special bath aids and specially designed eating utensils, with 68.2% of the SCUs reporting the former and 55.2% of SCUs reporting the latter. More SCUs reported use of emergency response systems, with 25.8% using such systems compared with 19.1% of other units.

3.6 Approach to Daily Activities

In order to illustrate the care environment in SCUs and in the Homes generally, respondents were provided with a list of statements about daily activities and asked whether their Home was "very much like this", "somewhat like this", or "not at all like this." The responses showed consensus among all units in some areas as well as diversity.

Almost all SCUs and Homes indicated they were "very much like this" in terms of having regularly scheduled meals and providing privacy when residents bathed. While most SCUs (77.5%) encouraged residents to decorate their rooms with their favourite belongings, this practice was more frequent in the Homes generally (90.2%).

The Homes generally were more likely than the SCUs to offer residents with moderate or severe dementia a choice in clothing and to require residents to be clean and dressed before meals. The SCUs were more likely to serve meals one course at a time, to toilet residents every two hours, and to allow residents to arise in the morning and go to bed at night when they wished. Compared with practice in the Homes generally, more SCUs indicated "Staff spend a good deal of time interacting with residents on an individual basis" (52.1% vs. 37.7%). Fewer SCUs indicated "Residents with moderate or severe dementia spend more time in group than in individual activities" (33.8% vs. 40.8%).

3.7 Use of Restraints

Few differences were observed between practices on SCUs and in the Homes generally. Virtually all Homes and SCUs reported using restraints under certain circumstances, usually as a safety measure. One-third of the Homes (31.6%) and 21.5% of the SCUs said they used a policy of least restraint.

When asked whether they had used any of a list of restraints at least once, 93.8% of SCUs reported using chemical restraints at least once compared with 86.5% of Homes generally. SCUs also reported use of the geri chair (84.4%), the lap belt (71.0%), and the jacket restraint (38.3%), with the somewhat fewer Homes reporting use of these restraints outside the SCU.

When asked whether certain types of restraints were used more or less often on the SCU compared with other units of the Home caring for residents with moderate or severe dementia, SCUs replied in various ways. While one-third of SCUs (35.3%) believed chemical restraints were used more often on the SCU, 22.0% believed they were used less frequently. One-third of respondents believed jacket restraints were used less frequently. Most SCUs (62.8%) agreed that lap belts are used about as frequently on the SCUs as elsewhere in the Home.

More SCUs reported consulting the family each time a restraint was used, with 81.2% following this policy compared with 63.1% of Homes.

3.8 Interventions for Problem Behaviours

The same types of interventions are used both on and outside SCUs, although a larger percentage of the SCUs indicated they used each intervention. Also, the SCUs were less likely to use an alarm to control wandering and more likely to create spaces for wandering than other areas of the Home.

The most frequently mentioned interventions for wandering on SCUs were provision of secure areas (73.2%), increasing staff (43.7%), and diversion tactics (35.2%). In response to abusive or aggressive behaviour, SCUs most frequently increase staff (74.6%), use a diversion tactic (40.8%), or a chemical restraint (31.0%).

The most frequent responses to agitated behaviour were increased staff (69.0%), diversion (63.4%), and chemical restraints (19.7%). Hoarding or rummaging were addressed through frequent room checks (56.3%), locked closets (36.6%), diversion (29.6%), and increased monitoring (23.9%). Most SCUs (98.6%) indicated they used regular toilet routines as a preventive measure for incontinence, although 40% also reported use of diapers.

3.9 Palliative Care

Just over half the SCUs (56.3%) and units elsewhere in the Home (57.4%) offer palliative care for residents with moderate or severe dementia. This care is typically provided on the unit in the resident's own bed, although SCUs were more likely than units elsewhere to provide care there (75.0% vs. 61.4%). Otherwise, palliative care usually is provided in a sick bay on the unit.

3.10 Programs and Services

SCUs are more likely to hold unit meetings to plan programs and services and meet more frequently for this purpose than is the practice elsewhere in the Home. Almost two-thirds of SCUs (63.4%) hold such meetings, compared with 47.5% of other units, and most (80.0%) meet once each month, compared with 69.1% of other units.

The SCUs and the Homes identified the same in-house programs as being the most effective for residents with moderate or severe dementia. While more than 30 programs were identified as being the most effective, the ones mentioned most frequently fell into eight categories. These were exercise related (53.5%), music related (53.5%), food related (40.8%), crafts and games (31.0%), social groups (26.8%), activities of daily living (18.3%), reality orientation (18.3%), and lifeskills (18.4%).

About one-third of the programs listed by the SCUs (each SCU could indicate up to four programs) were held once each week and included music or food-related programs plus reality orientation. One-fifth of programs (21.6%), such as crafts, are offered two or three times each week and 18.0% are offered five days weekly. SCUs have a larger proportion of programs offered daily compared with units elsewhere in the Home (15.0% compared with 9.7%), and most that offer exercise do so daily.

Most programs on SCUs (61.1%) are held on the unit itself rather than elsewhere in the Home, compared with 38.1% of programs offered generally in the Home. Most programs for residents with moderate or severe dementia on SCUs and elsewhere in the Home are group programs (69%) and fewer than 20% are strictly one-to-one programs.

Most programs offered generally in the Home (64.9%) involved residents with moderate or severe dementia as well as other residents. On SCUs, 43.5% of programs included both groups of residents.

In terms of outreach programming, fewer SCUs provided outreach programs compared with the Home in general (40.8% vs. 68.1%) and fewer believed this role would increase in the future (64.8% vs. 81.9%). Both groups believed the most beneficial outreach programs for residents with dementia were daycare, respite programs and meal programs.

3.11 Staffing Practices

Only about half the Homes and SCUs could provide information on staff/resident ratios. The average ratio on wards without residents with moderate or severe dementia in Homes that could provide this figure (N=48) was 1:15, in a range of 1:1 to 1:40.

Units with residents with moderate or severe dementia reported an average staff ratio of 1:9, in a range of 1:3 to 1:20.

SCUs reported an average ratio of between 1:6 to 1:8, in a range of 1:2 to 1:17.

Most of the SCUs and Homes believed these ratios allow staff to carry out most aspects of caring for residents with moderate or severe dementia, although both believed it did not permit programmed activities in the evening (approximately 80%) or to be responsive to residents' needs for individual attention (42.3% of SCUs and 47.7% of Homes.)

Most SCUs (60.9%) said staffing arrangements are the same on weekends as they are during the week. The SCUs were almost equally divided in terms of staffing rotation, with 38.6% indicating a specialized team that stays on the same shift (ie., only days or only nights), a specialized team that rotates two or more shifts within the unit (38.6%), and some other arrangement such as staff rotating through the Home (22.9%).

Most SCUs (77.3%) said staff on the unit received about the same number of hours of training as did staff working elsewhere in the Home with residents with moderate or severe dementia. The other SCUs said their staff received more training.

The extent of volunteer involvement is equally high on SCUs as on other units in the Home, with approximately 94% of SCUs and Homes reporting involvement of volunteers (including family members) in activities with residents with moderate or severe forms of dementia. However, in many respects, there is less volunteer involvement for residents with moderate or severe dementia on the SCU and elsewhere in the Home than there is for other residents.

Residents with moderate or severe dementia living on and outside SCUs receive about the same number of social visits. While few receive daily visitors (11.0% of SCU residents, 12.9% residents elsewhere), about one-third receive visitors about once a week. Most receive visitors less often.

3.12 Costs of Caring for Residents with Moderate or Severe Dementia

Few differences in the costs of caring for residents with moderate or severe dementia on or outside the SCU were identified by respondents. About two-thirds (62.1%) believed more is spent for personal care staff on SCUs and on design-related items (53.8%) and technology and security systems (79.0%).

3.13 Perceived Success of Special Care Units

Both the SCUs and the Homes in general believed the SCUs were more successful than units elsewhere at providing various aspects of care to residents with moderate or severe dementia, with the SCUs more likely than the Homes to believe in the success of the SCU. The SCUs were seen as more successful at ensuring resident's safety (85.9% of SCUs vs. 75.4% of Homes), responding to problem behaviours (74.6% vs. 68.6%), and providing appropriate programming (73.2% vs. 66.9%).

Respondents were also asked to indicate their level of agreement with a series of statements about the advantages or disadvantages of integrated and segregated care (such as SCUs) for residents with moderate or severe dementia. The SCUs and Homes in general agreed about the advantages and disadvantages of segregated care. However, the SCUs were more likely to agree that the needs of residents with dementia are different from those of other residents and are best met in a special care unit, that residents with dementia are sensitive to rejection from cognitively intact residents, and that a therapeutically-designed environment can best be created in separate units for residents with dementia.

SOMMAIRE

ÉTUDE DES PRATIQUES ACTUELLES EN MATIÈRE DE SOINS AUX PERSONNES ATTEINTES DE DÉMENCE DANS LES FOYERS POUR PERSONNES ÂGÉES DE L'ONTARIO

1.0 INTRODUCTION

1.1. Objectif de l'étude

En 1989, la Direction des services aux personnes âgées du ministère des Services sociaux et communautaires de l'Ontario a entrepris une étude globale sur les pratiques actuelles en matière de soins aux personnes atteintes de démence modérée ou grave dans les foyers pour personnes âgées. Le mandat de l'étude comportait deux objectifs :

- décrire et comparer l'éventail des moyens déployés pour s'occuper des pensionnaires atteints de démence dans les foyers pour personnes âgées de l'Ontario;
- décrire le rôle du service de soins spéciaux dans le traitement des personnes âgées atteintes de démence et les résultats constatés dans les services de soins spéciaux qui existent dans les foyers pour personnes âgées en Ontario.

Pour atteindre ces objectifs, on a confié à deux organismes, Flett Consulting Group Inc. et Social Data Research Ltd., le soin d'effectuer une enquête dans les 181 foyers pour personnes âgées de l'Ontario sur les pratiques en matière de soins en général et sur les soins prodigués dans les services de soins spéciaux. On a également examiné les résultats de la recherche dans le domaine des soins aux personnes âgées atteintes de démence. Pour obtenir les résultats de l'étude en trois volumes, s'adresser à :

Direction des services aux personnes âgées
Division des services communautaires de
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2.0 EXAMEN DES RÉSULTATS DE LA RECHERCHE

2.1 Prévalence des troubles mentaux

Selon quatre études sur la prévalence des troubles mentaux chez les pensionnaires des établissements de soins de longue durée, ceux-ci frappent de 52 à 94 pour 100 des pensionnaires. Selon une cinquième étude, 22 pour 100 des personnes âgées en établissement en Ontario souffriraient de troubles aigus de désorientation.

2.2 Pratiques en matière de soins aux pensionnaires atteints de démence

Les besoins particuliers des pensionnaires atteints de démence résultent des symptômes de leur maladie et de leurs relations avec autrui. Leur besoin de soins spéciaux est lié à leurs problèmes de comportement, à leur faculté de prendre des décisions, à leurs déficits fonctionnels, à leurs symptômes psychotiques, notamment les hallucinations. Ils ont aussi tendance à souffrir de dépression et d'angoisse. À d'autres points de vue, les pensionnaires atteints de démence ont les mêmes besoins que les autres personnes âgées fragiles que les meilleures pratiques de soins comblent parfaitement. Les bonnes pratiques de soins résultent de l'évaluation globale et de la réévaluation par une équipe de soins pluridisciplinaire de la mise en place d'un programme de soins fondé sur les résultats des évaluations et de son exécution rigoureuse.

2.3 Aménagement du cadre de vie des pensionnaires atteints de démence

Les éléments du cadre de vie qui sont importants pour toutes les personnes âgées sont conçus pour compenser l'affaiblissement des capacités physiques et pour favoriser les bonnes pratiques de soins. Les caractéristiques qui concernent particulièrement les personnes âgées atteintes de démence sont celles qui ont trait à l'habitude d'errer au hasard ou de faire les cent pas, à leur perte de facultés intellectuelles et aux autres symptômes de la maladie. Pour créer le cadre de vie qui leur convient, il faut adhérer aux préceptes suivants : créer un milieu accueillant, apporter le soutien nécessaire pour compenser l'affaiblissement des facultés des pensionnaires, supprimer les trompe-l'oeil, comme les papiers peints à motifs de briques, favoriser le calme et la détente, bien définir les espaces et mettre l'accent sur la santé et la sécurité des pensionnaires.

2.4 Services de soins spéciaux

Les services de soins spéciaux sont définis dans la recherche comme des services séparés, comportant des moyens de soutien des pensionnaires atteints de démence et des programmes spécialisés, et le personnel qui les assure a reçu une formation spécialisée. Dans l'état actuel des choses, on constate que les services varient beaucoup d'un établissement à l'autre, et que le terme «soins spéciaux» n'indique parfois qu'une légère différence par rapport aux normes de l'établissement.

C'est la raison pour laquelle il était difficile d'évaluer l'efficacité des services de soins spéciaux. Les résultats des recherches récentes n'ont pas permis de dégager des données uniformes sur les avantages ou les inconvénients de ces services. Certains programmes de soins spéciaux prétendent avoir réussi à améliorer le comportement des pensionnaires en matière de convenances, à réduire les cas de comportements extrêmes et à ralentir la diminution des facultés par la suite. Cependant, on n'a pas constaté de progrès uniformes dans les domaines où les pensionnaires sont les plus atteints, comme le langage, la capacité motrice et la mémoire.

La taille des services de soins spéciaux est généralement déterminée par la disponibilité de locaux et les contraintes budgétaires, plutôt que par des considérations théoriques sur la taille idéale. On considérait que les services de moins de 20 lits étaient l'idéal. Cependant, les services comptaient en général entre 20 et 34 lits.

Il n'existe pas de critères d'admission dans un service de soins spéciaux généralement reconnus. Cependant, un grand nombre de ces services n'acceptent que les pensionnaires atteints de démence irréversible qui présentent des problèmes de comportement et qui peuvent profiter du programme. Dans certains établissements, les pensionnaires restent dans le service de soins spéciaux même lorsque leur situation s'aggrave et qu'ils nécessitent davantage de soins. D'autres renvoient les pensionnaires lorsque, pour des raisons de détérioration physique, cognitive ou du comportement, le programme ne peut plus rien leur apporter.

Le nombre de pensionnaires par préposé aux soins directs (poste du jour) dans trois sondages des services de soins spéciaux allait de 1 pour 3 et 1 pour 4 à entre 1 pour 7 et 1 pour 12. Certains services modifient l'attribution habituelle des tâches et d'autres engagent du personnel supplémentaire en fin d'après-midi et en soirée. La formation offerte varie considérablement d'un service à l'autre.

L'aménagement du cadre de vie varie également. Celui-ci, ainsi que la formation du personnel et les thérapies spécialisées constituent les principaux postes de dépenses des services de soins spéciaux.

Bien des établissements ne disposent pas des ressources voulues pour créer des services de soins spéciaux et s'efforcent donc de trouver des moyens d'améliorer la qualité des soins pour tous les pensionnaires avec un budget très limité. La recherche a montré que certains foyers réorganisaient la gestion du personnel et les emplois du temps des programmes, lançaient des programmes internes de jour et effectuaient de modestes adaptations du cadre de vie.

3.0 SONDAGE AUPRÈS DES FOYERS POUR PERSONNES ÂGÉES

On a effectué un sondage par la poste auprès des 181 foyers pour personnes âgées de l'Ontario durant l'été de 1990 pour recueillir des données sur les caractéristiques des pensionnaires et une description des règlements et des pratiques en matière de soins aux personnes âgées atteintes de démence dans les services généraux du foyer. On a également demandé à tous les foyers pour personnes âgées s'ils disposaient d'un service réservé aux pensionnaires atteints de démence et, dans l'affirmative, on leur a demandé de remplir un deuxième questionnaire sur le profil des pensionnaires et les pratiques en matière de soins dans ces services.

Nous avons reçu 133 questionnaires dûment remplis, indiquant un taux de participation de 80 pour 100 (133/166); nous avons redressé l'échantillon de base et supprimé 15 foyers qui n'acceptaient pas les pensionnaires atteints de démence. Soixante-sept foyers ont rempli le questionnaire sur les services de soins spéciaux. Deux foyers comptaient 2 services de soins spéciaux et un autre en comptait 3, ce qui donne un total de 71 réponses.

Le nombre de pensionnaires dans chaque foyer variait également; 37,4 pour 100 avaient moins de 100 pensionnaires, 37,4 pour 100 comptaient entre 100 et 199 pensionnaires et 25,1 pour 100 avaient 200 pensionnaires ou plus.

La plupart des remarques qui suivent ont trait aux services de soins spéciaux. On effectue des comparaisons avec les services généraux qui accueillent des pensionnaires atteints de démence modérée ou grave lorsqu'on constate des différences.

3.1 Date de création, emplacement et effectifs des services de soins spéciaux

Il y a longtemps que les services de soins spéciaux existent dans les foyers pour personnes âgées en Ontario. S'il est vrai que 40 pour 100 des foyers qui ont ces services ont signalé qu'ils avaient été créés au cours des 10 dernières années, 44 pour 100 d'entre eux comptaient déjà des services de soins spéciaux avant 1970.

La plupart des services (67,1 pour 100) sont situés au rez-de-chaussée. Chaque service accueille un nombre différent de pensionnaires : 9,8 pour 100 d'entre eux signalaient qu'ils avaient moins de 20 pensionnaires dans chaque service, 28,2 pour 100 en avaient entre 20 et 29, 26,8 pour 100 dénombraient entre 30 et 39 pensionnaires et 35,2 pour 100 accueillaient 40 pensionnaires ou plus.

3.2 Profil des pensionnaires

On a demandé aux foyers de fournir des renseignements sur trois groupes de pensionnaires : tous les pensionnaires du foyer, les pensionnaires atteints de démence modérée ou grave (qui ne se trouvaient pas dans des services de soins spéciaux) et les pensionnaires des services de soins spéciaux. La plupart des pensionnaires des foyers étaient des femmes (72 pour 100) et la plupart étaient célibataires (86,2 pour 100). La moitié des pensionnaires étaient âgés de plus de 85 ans (49,4 pour 100) et la moitié (50,3 pour 100) avaient besoin de l'aide des préposés pour au moins trois activités quotidiennes. Près de un tiers (38,2 pour 100) pouvaient se déplacer seuls sans l'aide d'une canne ou d'un déambulateur, alors que les autres pouvaient se déplacer avec une canne ou un déambulateur (22 pour 100), en fauteuil roulant (15,6 pour 100) et le reste avait besoin de l'aide du personnel pour se déplacer (24,2 pour 100).

Le personnel a déclaré que, selon les définitions qu'en donnaient les chercheurs, 66,6 pour 100 des pensionnaires des foyers souffraient d'une forme ou d'une autre de démence. Alors que seuls 17,5 pour 100 des pensionnaires avaient été diagnostiqués comme atteints de la maladie d'Alzheimer ou d'une démence connexe, 40,8 pour 100 souffraient d'une forme modérée ou grave de démence, selon les préposés.

On a constaté peu de différences entre l'ensemble des pensionnaires et les pensionnaires atteints de démence modérée ou grave (qui ne se trouvaient pas dans des services de soins spéciaux) en ce qui concerne l'âge, le sexe et la situation de famille. Cependant, les pensionnaires atteints de démence modérée ou grave (qui ne se trouvaient pas dans des services de soins spéciaux) exigeaient plus d'aide dans les activités quotidiennes puisque 97,1 pour 100 d'entre eux avaient besoin d'aide pour au moins trois activités quotidiennes, par rapport à 50,3 pour 100 pour l'ensemble des pensionnaires du foyer. Les pensionnaires atteints de démence modérée ou grave étaient également plus nombreux à avoir besoin d'aide pour se déplacer, puisque 43,5 pour 100 ne pouvaient le faire seuls par rapport à 24,2 pour 100 pour l'ensemble des pensionnaires du foyer.

Les pensionnaires des services de soins spéciaux étaient plus jeunes que l'ensemble des pensionnaires du foyer : 31,8 pour 100 d'entre eux étaient âgés de plus de 85 ans, par rapport à 49,4 pour 100 pour l'ensemble des pensionnaires. Selon les évaluations, la plupart des pensionnaires des services de soins spéciaux (93,5 pour 100) étaient atteints de démence modérée ou grave et 83,5 pour 100 d'entre eux avaient besoin d'aide pour au moins trois activités quotidiennes. Les pensionnaires des services de soins spéciaux arrivaient mieux à se déplacer que le reste des pensionnaires des foyers puisque 63,3 pour 100 d'entre eux pouvaient se déplacer seuls sans l'aide d'une canne ou d'un déambulateur, par rapport à 38,2 pour 100 de l'ensemble des pensionnaires.

On n'a constaté aucune différence entre les pensionnaires atteints de démence modérée ou grave à l'intérieur ou à l'extérieur des services de soins spéciaux en ce qui concerne l'errance, l'agitation et l'incontinence. Trente pour cent de chaque groupe erraient, 48 pour 100 de chaque groupe étaient agités et 68,8 pour 100 des pensionnaires des services de soins spéciaux étaient incontinents, par rapport à 61,9 pour 100 des pensionnaires atteints de démence modérée ou grave qui ne se trouvaient pas dans des services de soins spéciaux. Cependant, les pensionnaires des services de soins spéciaux étaient plus portés à afficher un comportement grossier ou agressif (69,9 pour 100 par rapport à 29,4 pour 100) et avaient plus tendance à amasser des choses ou à farfouiller (74,1 pour 100 par rapport à 17,5 pour 100).

3.3 Politiques régissant l'admission et la mise en congé des pensionnaires

En ce qui concerne les critères d'admission aux services de soins spéciaux, on citait le plus souvent les dangers auxquels on s'expose, en partie en raison de l'errance (85,7 pour 100), la présence de comportements qui gênent les autres (84,1 pour 100) et le diagnostic d'une démence irréversible (74,3 pour 100). Les services de soins spéciaux utilisaient plus souvent des outils d'évaluation formelle ou structurée pour évaluer la situation des pensionnaires atteints de démence modérée ou grave que ce n'était le cas en général dans les foyers pour personnes âgées. Un grand nombre utilisait le test Folstein Mini-Mental State Examination.

En dehors du décès, les raisons de départ les plus souvent citées pour les pensionnaires atteints de démence modérée ou grave étaient les mêmes dans les services de soins spéciaux que dans l'ensemble du foyer : les pensionnaires ont besoin de soins psychiatriques spécialisés, les pensionnaires affichent un comportement violent et les pensionnaires exigent plus de soins que le service n'est en mesure de leur fournir.

Les auxiliaires en soins infirmiers inscrits s'occupaient davantage des évaluations au moment de l'admission au service et participaient aux décisions relatives au transfert et à la mise en congé des pensionnaires des services de soins spéciaux que dans le foyer en général.

3.4 Planification des soins

La plupart des services de soins spéciaux (95,7 pour 100) ont signalé qu'ils effectuaient plus d'une réévaluation par an et 82,1 pour 100 n'effectuaient pas plus de quatre réévaluations annuelles. Tandis que deux tiers des services (64,8 pour 100) ont déclaré qu'ils réévaluaient leurs pensionnaires aussi souvent que les pensionnaires atteints de démence modérée ou grave des autres services, un tiers (33,8 pour 100) ont signalé qu'ils réévaluaient ces pensionnaires plus souvent que les autres patients, surtout pour surveiller et pallier les problèmes de comportement. Les membres de la famille interviennent plus souvent dans ces réévaluations des pensionnaires des services de soins spéciaux que dans celles des autres pensionnaires du foyer. En effet, 62,3 pour 100 des services de soins spéciaux ont indiqué que la famille participait généralement aux décisions par rapport à 50,4 pour 100 des répondants au sondage sur l'ensemble des foyers.

La plupart des services de soins spéciaux (81,7 pour 100) ont signalé qu'ils révisaient le programme de soins de leurs pensionnaires aussi souvent que c'était le cas ailleurs dans le foyer. On révise les programmes chaque mois dans la moitié des services (50,7 pour 100) et environ une fois par an, dans les autres services.

3.5 Actions sur le milieu et aides technologiques

Les services de soins spéciaux étaient plus portés que les autres services des foyers à adopter des mesures pour accroître la sécurité du service. Un plus grand nombre d'entre eux ont signalé les systèmes d'alerte, de codage ou de fermeture sécuritaire aux portes de sortie du service (100 pour 100 par rapport à 83,1 pour 100), la protection des aires à l'extérieur utilisées par les pensionnaires (71 pour 100 par rapport à 52,2 pour 100), un système de fermeture des portes d'ascenseur adjacent au service (45,8 pour 100 par rapport à 36,5 pour 100) et l'utilisation de miroirs convexes dans le service (20,6 pour 100 par rapport à 10,4 pour 100). Très peu de foyers utilisaient des caméras vidéo.

Il arrivait plus souvent que les services de soins spéciaux adoptent d'autres mesures de sécurité telles que la fermeture des portes au moyen d'un système de sécurité à clé ou à combinaison (83,8 pour 100 par rapport à 48,3 pour 100), le port de bracelets d'identité (64,2 pour 100 par rapport à 55,8 pour 100), un système de codage ou de fermeture à clé des ascenseurs (40,7 pour 100 par rapport à 16,6 pour 100), la pose de détecteurs électroniques sur les portes (39,4 pour 100 par rapport à 35,6 pour 100) et de détecteurs électroniques dans les ascenseurs (5,2 pour 100 par rapport à 12 pour 100).

La plupart des services de soins spéciaux et des autres services du foyer plaçaient des panneaux sur les portes des pensionnaires pour lutter contre la désorientation dans le temps et dans l'espace. On constate peu de différences entre les services, si ce n'est que les services de soins spéciaux suppriment les stimulants troublants comme les oeuvres d'art.

Les services de soins spéciaux étaient plus susceptibles que les autres services de permettre aux patients de déambuler et de réduire les bousculades chez les pensionnaires atteints de démence modérée ou grave. Il arrivait plus souvent que les services de soins spéciaux prévoient des endroits à l'extérieur (82,9 pour 100 par rapport à 43,9 pour 100) ou des endroits à l'intérieur où ils pourraient errer (72,5 pour 100 par rapport à 33,3 pour 100) et des salles communes plus grandes (48,5 pour 100 par rapport à 25,7 pour 100).

Les services de soins spéciaux étaient également plus susceptibles de signaler qu'ils avaient adopté des mesures de lutte contre le bruit - utilisation étudiée de musique de fond (49,3 pour 100 par rapport à 38,6 pour 100), élimination de l'interphone ou du système de sonorisation (31,4 pour 100 par rapport à 28,1 pour 100). Cependant, les autres services ont plus souvent de la moquette ou d'autres matériaux d'insonorisation (40 pour 100 par rapport à 29,6 pour 100).

La plupart des services de soins spéciaux et des autres services du foyer s'efforcent de compenser par divers moyens les déficits sensoriels des pensionnaires. De 50 à 60 pour 100 des deux types de services ont signalé avoir intensifié l'éclairage ambiant, adopté des mesures pour réduire les réflexions sur le sol, utilisé des finis texturés et évité les variations d'éclairage. Dans les services de soins spéciaux, on utilise souvent des couleurs contrastantes pour indiquer les différences (par exemple entre la porte et la poignée, la vaisselle et la table, le sol et les murs) puisque 81,4 pour 100 d'entre eux appliquaient ce principe par rapport à 74,8 pour 100 pour l'ensemble des foyers. En outre, les services de soins spéciaux avaient tendance également à éliminer le contraste là où il n'y a pas de différences (par exemple, les motifs des revêtements de sol).

On n'a guère constaté de différence entre les services de soins spéciaux et les autres services du foyer en ce qui concerne l'utilisation d'aides spéciales pour le bain et de couverts spécialement adaptés : 68,2 pour 100 pour les premiers et 55,2 pour 100 pour les seconds, dans les services de soins spéciaux. Un plus grand nombre de services de soins spéciaux signalaient avoir adopté un système d'alerte, puisque 25,8 pour 100 d'entre eux en étaient dotés par rapport à 19,1 pour 100 pour les autres services.

3.6 Déroulement des activités quotidiennes

Pour se faire une idée du déroulement des activités dans les services de soins spéciaux et dans l'ensemble du foyer, on a fait parvenir aux répondants une liste d'énoncés sur les activités quotidiennes en leur demandant si les énoncés décrivaient ce qui se passait «en général», «parfois» ou «pas du tout» dans leur établissement. Dans certains domaines, les réponses étaient les mêmes et dans d'autres, il existait des divergences.

Presque tous les services de soins spéciaux et les foyers ont indiqué qu'ils servaient les repas à certaines heures et qu'ils s'arrangeaient pour respecter l'intimité des pensionnaires durant leur bain. La plupart des services de soins spéciaux (77,5 pour 100) encourageaient les pensionnaires à décorer leur chambre avec des objets personnels auxquels ils tiennent. Cependant, cette pratique était beaucoup plus répandue dans l'ensemble du foyer (90,2 pour 100).

Les foyers étaient beaucoup plus nombreux que les services de soins spéciaux à autoriser les pensionnaires atteints de démence modérée ou grave à choisir leurs vêtements et à exiger qu'ils se lavent et s'habillent avant les repas. Les services de soins spéciaux avaient davantage tendance à servir les repas un plat à la fois, à obliger les pensionnaires à aller aux toilettes toutes les deux heures et à leur permettre de se lever le matin et de se coucher le soir quand ils en avaient envie. Comparés à l'ensemble des services du foyer, davantage de services de soins spéciaux ont signalé que «le personnel passait beaucoup de temps en interaction à titre individuel pour les pensionnaires» (52,1 pour 100 par rapport à 37,7 pour 100). Moins de services de soins spéciaux ont indiqué que les «pensionnaires atteints de démence modérée ou grave consacrent plus de temps aux activités collectives qu'aux activités individuelles» (33,8 pour 100 par rapport à 40,8 pour 100).

3.7 Recours à la contrainte

On constatait peu de différences entre les services de soins spéciaux et l'ensemble du foyer à cet égard. Pratiquement tous les foyers et tous les services de soins spéciaux ont déclaré avoir recours à la contrainte dans certaines circonstances, généralement par précaution. Un tiers des foyers (31,6 pour 100) et 21,5 pour 100 des services de soins spéciaux ont déclaré qu'ils avaient le moins possible recours à la contrainte en règle générale.

Lorsqu'on leur a demandé s'ils avaient utilisé au moins une fois une des méthodes de contrainte énumérées, 93,8 pour 100 des services de soins spéciaux ont signalé avoir eu recours aux médicaments au moins une fois par rapport à 86,5 pour 100 des foyers en général. Les services de soins spéciaux ont également déclaré utiliser des fauteuils de gériatrie (84,4 pour 100), des ceintures (71 pour 100) et des camisoles de force (38,3 pour 100) tandis qu'un nombre moins important de foyers ont signalé utiliser ces méthodes ailleurs que dans les services de soins spéciaux.

Lorsqu'on leur a demandé quelles mesures de contrainte étaient utilisées plus souvent ou moins souvent dans les services de soins spéciaux par rapport aux autres services du foyer qui s'occupent de pensionnaires atteints de démence modérée ou grave, la réponse des services de soins spéciaux variait beaucoup. Un tiers des services de soins spéciaux (35,3 pour 100) estimaient que les médicaments étaient utilisés plus souvent dans leur service et 22 pour 100 ont déclaré y avoir recours moins souvent. Un tiers des répondants ont déclaré qu'ils utilisaient les camisoles de force moins souvent. La plupart des services de soins spéciaux (62,8 pour 100) ont reconnu que les ceintures étaient utilisées aussi souvent dans les services de soins spéciaux que dans les autres services du foyer.

Davantage de services de soins spéciaux ont déclaré qu'ils consultaient la famille chaque fois qu'ils avaient recours à la contrainte, puisque 81,2 pour 100 d'entre eux avaient adopté cette politique par rapport à 63,1 pour 100 des foyers.

3.8 Interventions relatives aux problèmes de comportement

Les services de soins spéciaux ont recours aux mêmes types d'intervention que les autres services du foyer, bien qu'un pourcentage plus élevé d'entre eux indiquent utiliser chaque type d'intervention. En outre, les services de soins spéciaux ont moins souvent recours aux systèmes d'alerte pour surveiller les pensionnaires qui errent sans but, et ils sont plus nombreux que les autres services du foyer à créer des espaces où ils peuvent errer.

Parmi les interventions les plus souvent mentionnées à propos des pensionnaires qui errent dans les services de soins spéciaux, signalons l'aménagement d'endroits où ils peuvent errer sans danger (73,2 pour 100), l'augmentation des effectifs (43,7 pour 100) et les tactiques de diversion (35,2 pour 100). En ce qui concerne le comportement grossier ou agressif, la plupart des services de soins spéciaux augmentaient les effectifs (74,6 pour 100), avaient recours à des tactiques de diversion (40,8 pour 100) ou aux médicaments (31 pour 100).

La réaction la plus fréquente à l'agitation des pensionnaires était l'augmentation des effectifs (69 pour 100), les tactiques de diversion (63,4 pour 100) et l'administration de médicaments (19,7 pour 100). Pour venir à bout des pensionnaires qui amassent des choses ou farfouillent, on fouillait leur chambre fréquemment (56,3 pour 100), on fermait les placards à clé (36,6 pour 100), on avait recours à des tactiques de diversion (29,6 pour 100) et on les surveillait de plus près (23,9 pour 100). La plupart des services de soins spéciaux (98,6 pour 100) ont signalé qu'ils emmenaient régulièrement les pensionnaires aux toilettes pour parer aux inconvénients de l'incontinence, bien que 40 pour 100 déclaraient également utiliser des couches.

3.9 Soins palliatifs

Un peu plus de la moitié des services de soins spéciaux (56,3 pour 100) et des autres services du foyer (57,4 pour 100) offrent des soins palliatifs aux pensionnaires atteints de démence modérée ou grave. Ces soins sont généralement prodigués au pensionnaire dans son propre lit, dans le service même, bien que ce soit surtout la façon de procéder des services de soins spéciaux (75 pour 100 par rapport à 61,4 pour 100). Dans les autres cas, les soins palliatifs sont prodigués à l'infirmerie du service.

3.10 Programmes et services

Les services de soins spéciaux ont tendance à organiser plus de réunions du personnel pour planifier les programmes et les services que les autres services du foyer. Près des deux tiers des services de soins spéciaux (63,4 pour 100) ont de telles réunions, par rapport à 47,5 pour 100 pour les autres services, et la plupart d'entre eux (80 pour 100) se réunissent une fois par mois, par rapport à 69,1 pour 100 dans les autres services.

Les services de soins spéciaux et les foyers ont cité les mêmes programmes de l'établissement comme étant les plus efficaces pour soigner les pensionnaires atteints de démence modérée ou grave. En tout, ils ont cité plus de 30 programmes qu'ils considèrent les plus efficaces, et ceux les plus souvent cités relèvent de huit domaines : l'exercice physique (53,5 pour 100), la musique (53,5 pour 100), l'alimentation (40,8 pour 100), les travaux manuels et les jeux (31 pour 100), la vie sociale (26,8 pour 100), les activités de la vie de tous les jours (18,3 pour 100), l'orientation vers la réalité (18,3 pour 100) et l'apprentissage fonctionnel (18,4 pour 100).

Près de un tiers des programmes énumérés par les services de soins spéciaux (chaque service de soins spéciaux pouvait citer jusqu'à quatre programmes) ont lieu une fois par semaine et portent sur des activités axées sur la musique ou l'alimentation, en plus de l'orientation vers la réalité. Un cinquième des programmes (21,6 pour 100), les travaux manuels par exemple, ont lieu deux ou trois fois par semaine et 18 pour 100, cinq jours par semaine. Les services de soins spéciaux offrent une plus grande proportion de programmes quotidiens que les autres services du foyer (15 pour 100 par rapport à 9,7 pour 100) et la plupart de ceux qui offrent des programmes d'exercice physique le font tous les jours.

La plupart des programmes des services de soins spéciaux (61,1 pour 100) ont lieu dans le service même, plutôt qu'ailleurs dans le foyer, alors que dans le reste du foyer, seuls 38,1 pour 100 des programmes sont dans ce cas. La plupart des programmes destinés aux pensionnaires atteints de démence modérée ou grave des services de soins spéciaux et des autres services du foyer sont des programmes collectifs (69 pour 100), et moins de 20 pour 100 sont à proprement parler des programmes individuels.

La plupart des programmes offerts généralement dans le foyer (64,9 pour 100) acceptent des pensionnaires atteints de démence modérée ou grave ainsi que d'autres pensionnaires. Dans les services de soins spéciaux, 43,5 pour 100 des programmes comprennent des pensionnaires des deux groupes.

En ce qui concerne les programmes d'extension, moins de services de soins spéciaux en ont que l'ensemble du foyer (40,8 pour 100 par rapport à 68,1 pour 100). Ils sont aussi moins nombreux à déclarer que la situation va changer dans l'avenir (64,8 pour 100 par rapport à 81,9 pour 100). Les deux groupes estiment que les programmes d'extension les plus avantageux pour les pensionnaires atteints de démence sont les services de garde de jour, les programmes de relève et les programmes de repas.

3.11 Pratiques relatives à la dotation en personnel

À peine la moitié des foyers et des services de soins spéciaux ont pu nous donner des renseignements sur le nombre de pensionnaires par préposé. La proportion est en moyenne de 15 pensionnaires par préposé (variant entre 1 et 40 par préposé) dans les salles où il n'y a pas de pensionnaires atteints de démence modérée ou grave, ceci dans les foyers pour personnes âgées qui ont fourni un chiffre (N=48).

Les services qui accueillent des pensionnaires atteints de démence modérée ou grave indiquent que la proportion est en moyenne de 9 pensionnaires par préposé (variant entre 3 et 20 par préposé).

Les services de soins spéciaux indiquent que la proportion est en moyenne de 6 à 8 pensionnaires par préposé (variant entre 2 et 17 par préposé).

La plupart des services de soins spéciaux et des foyers estiment que ces proportions permettent à leur personnel de prodiguer la plupart des soins aux pensionnaires atteints de démence modérée ou grave. Cependant, les deux groupes reconnaissent que cela ne leur permet pas d'organiser des activités le soir (près de 80 pour 100), ni d'être sensibles aux besoins d'attention individuelle des pensionnaires (42,3 pour 100 des services de soins spéciaux et 47,7 pour 100 des foyers).

La plupart des services de soins spéciaux (60,9 pour 100) déclarent que les effectifs sont les mêmes la fin de semaine que la semaine. On constate une répartition presque égale dans les services de soins spéciaux en termes de rotation du personnel : 38,6 pour 100 indiquent qu'une équipe spécialisée travaille toujours le même quart (c'est-à-dire, soit le jour, soit la nuit), et 38,6 pour 100 d'entre eux ont une équipe spécialisée qui fait deux ou plusieurs quarts par rotation dans le service; d'autres services ont un système de rotation du personnel sur l'ensemble du foyer (22,9 pour 100).

La plupart des services de soins spéciaux (77,3 pour 100) déclarent que le personnel du service a effectué plus ou moins le nombre d'heures de formation que celui des autres services du foyer qui s'occupent de pensionnaires atteints de démence modérée ou grave. Les autres services de soins spéciaux indiquent que leur personnel a reçu une formation supplémentaire.

La participation de bénévoles est aussi élevée dans les services de soins spéciaux que dans les autres services du foyer, puisque près de 94 pour 100 des services de soins spéciaux et des foyers peuvent compter sur la participation des bénévoles (y compris les membres de la famille) aux activités destinées aux pensionnaires atteints de démence modérée ou grave. Cependant, à bien des égards, on constate que les bénévoles s'occupent moins des pensionnaires atteints de démence modérée ou grave dans les services de soins spéciaux et ailleurs dans le foyer que des autres pensionnaires.

Les pensionnaires atteints de démence modérée ou grave qui sont dans les services de soins spéciaux ou ailleurs reçoivent à peu près le même nombre de visiteurs. Peu d'entre eux ont des visiteurs chaque jour (11 pour 100 des pensionnaires des services de soins spéciaux par rapport à 12,9 pour 100 des autres pensionnaires). Près de un tiers d'entre eux ont des visiteurs une fois par semaine. La plupart d'entre eux ont des visiteurs moins souvent.

3.12 Coût des soins aux pensionnaires atteints de démence modérée ou grave

On constate peu de différences dans le coût des soins destinés aux pensionnaires atteints de démence modérée ou grave, qu'ils soient dans les services de soins spéciaux ou ailleurs dans le foyer. Près de deux tiers des répondants (62,1 pour 100) signalent que l'on dépense davantage pour les préposés aux soins personnels dans les services de soins spéciaux, pour l'aménagement du cadre de vie (53,8 pour 100) et pour le système de sécurité et les aides technologiques (79 pour 100).

3.13 Opinion sur les services de soins spéciaux

Les services de soins spéciaux et les foyers en général estiment que les services de soins spéciaux réussissent mieux que les autres services à fournir les divers soins dont ont besoin les pensionnaires atteints de démence modérée ou grave. Les services de soins spéciaux sont plus nombreux à croire à leur réussite que les foyers. On considère que les services de soins spéciaux réussissent mieux à assurer la sécurité des pensionnaires (85,9 pour 100 des services de soins spéciaux par rapport à 75,4 pour 100 des foyers), à venir à bout des comportements difficiles (74,6 pour 100 par rapport à 68,6 pour 100) et à fournir des programmes appropriés (73,2 pour 100 par rapport à 66,9 pour 100).

On a également demandé aux répondants de donner leur avis sur une série de déclarations décrivant les avantages et les inconvénients des services intégrés et des services distincts (comme les services de soins spéciaux) pour les pensionnaires atteints de démence modérée ou grave. Les services de soins spéciaux et les foyers en général sont d'accord sur les avantages et les inconvénients des services distincts. Cependant, les services de soins spéciaux sont plus enclins à reconnaître que les pensionnaires atteints de démence ont des besoins différents de ceux des autres pensionnaires, des besoins que le service de soins spéciaux peut mieux satisfaire, car les pensionnaires atteints de démence sont sensibles au rejet des pensionnaires dont les facultés intellectuelles sont intactes. Ils estiment qu'il est plus facile de créer un environnement thérapeutique dans des services réservés aux pensionnaires atteints de démence.

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EXECUTIVE SUMMARY

This is Volume I of A Study of Current Practices Related to the Caring for Persons with Dementia in Ontario's Homes for the Aged, undertaken for the Residential Services Branch of Ontario's Ministry of Community and Social Services. The terms of reference for the study identified two objectives:

- to describe and compare the range of strategies and techniques used for managing residents with dementia in Ontario's Homes for the Aged; and
- to describe, as a special focus, the role of the special care unit in caring for the elderly with dementia, the unique features of the special care unit, and the experiences in using special care units in Ontario's Homes for the Aged.

These objectives are addressed directly in Volumes II and III of the study, describing surveys of Ontario's Homes for the Aged and Special Care Units within the Homes. The literature review described here provides a context for the survey findings.

2.0 Profiles of Long-Term Care Facilities and their Residents with Dementia

Four studies of the prevalence of mental disorders among residents of long-term care facilities estimated prevalence in a range of between 52 and 94 percent of residents. A fifth study estimated that 22 percent of institutionalized elderly persons in Ontario had severe disorientation.

3.0 Philosophy of Care

The philosophy of care is a set of assumptions or values about a program and the people in it. It embraces environmental design, programming, staffing, and other aspects of the care environment that can be orchestrated to support the resident with dementia.

4.0 Care Practices for Residents with Dementia

The special needs of residents with dementia arise from the symptoms of their disorder and their interactions with other persons. Their special needs are related to problem behaviours, competency to make decisions, functional deficits, psychotic symptoms such as hallucinations, and suffering related to depression and anxiety. In other respects, the needs of residents with dementia are the same as those of other frail, elderly residents and are met through best practices of care.

Good care practice is based on comprehensive assessment and reevaluation, development of a care plan based on all assessment findings, and conscientious execution of the care plan.
Assessments should be conducted by an interdisciplinary team. Components described in the literature vary somewhat but frequently include a medical examination, psychological profile, mental status evaluation or testing for depression and dementia, a social/family history, environmental safety (in the individual's home), and behaviour assessment.

Based on this assessment, the care plan describes the resident's problems and needs, the goals of the care plan, the interventions to be used to achieve these goals, and the persons(s) responsible for implementing the strategies. Care plans are important in identifying problem behaviours and their underlying medical, psychiatric or environmental/social causes, and in targeting solutions to address one or more underlying causes.

5.0 Programs and Services for Residents with Dementia

Programs are the recreational and therapeutic activities typically scheduled for a few times during the day, as well as the residents' activities of daily living and housekeeping activities. Programs and their goals reflect the philosophy of care within a facility; for example, a philosophy favouring personal control and decision-making would lead to programs that offer residents a choice in participating (or declining to participate) in activities that reflect their personal talents, values or interests. Programs should reflect resident's needs and interests as indicated in the care plan and should be assessed as the illness progresses, to ensure that activities are within their capabilities.

The approach to activities for residents with dementia can be more important than the activities themselves, with a flexible and relaxed approach contributing to program success. Residents with dementia often fail to benefit from group programs planned for the general population of a long-term care facility, but most facilities lack the staff or resources to offer individual programs extensively. The benefits of individual and group programs specially designed for residents with dementia are described in the literature in terms of removal of excess disability and improvement in social functioning. However, the effectiveness of various interventions is difficult to measure because of difficulties in obtaining adequate sample sizes and control groups, inadequate instruments for capturing subtle changes in behaviour, lack of information about behaviour at various stages of a dementing illness, and other such factors.

6.0 Staff and Staff Training

There appeared to be general agreement in the literature concerning the need for a multidisciplinary care team that at times includes all staff. Although rotating staff on units caring for residents with dementia has been described as a means of relieving stress among staff, permanent staffing offers such benefits as greater continuity for residents, increased staff commitment to programming and implementation, and positive group dynamics.

Staff training is as important as physical design or programming, in terms of its contribution to a therapeutic milieu. Staff require basic training and continuing education delivered through a variety of modes. Possible topics include ongoing assessment of residents' needs, the role of independence in maintaining self-esteem, and the role of residents' families.

7.0 Environmental Design for Residents with Dementia

Environmental features important to all elderly include those intended to support decreased physical abilities and support good care practices. Features relevant to the elderly with dementia are features responding to wandering or pacing, loss of judgment, and other manifestations of the illness.

While there are several good models for environmental design, basic precepts they share include creation of a homelike environment; support to compensate for residents' diminished capabilities; avoidance of misleading cues about the environment, such as brick-patterned wallpaper; calm and quiet; clearly differentiated spaces; and a focus on residents' health and safety.

8.0 The Role of Families and Volunteers

Family visiting provides personal services for residents, affects the amount and type of services provided by staff, and has a therapeutic effect on resident well-being. Family members can also participate in care planning.

Family involvement may require supports from the facility, such as a liaison officer, support groups, and family conferences. After admission, such supports also help families with their feelings of loss and grief and provides information and reassurance.

9.0 Special Care Units

Special care units are defined variously in the literature as separate units featuring supportive design for residents with dementia, with specialized programs and trained staff. In practice, units for residents with dementia vary considerably and the term "special care" may simply indicate some variation from the facility's standard practice.

This variability has made it difficult to assess the effectiveness of special care units, and recent reviews of the literature have found no consistent research data on the benefits or disadvantages of these units. Some special care programs report initial improvements in terms of increases in socially appropriate behaviour and decreases in extreme behaviour among residents, with less precipitous decline thereafter. Programs fail to find consistent improvement in areas that are likely impaired by dementia, such as language skills, motor skills, and memory.

The size of special care units usually is determined by available space and budgets, rather than by theoretical considerations of optimal size. While units of fewer than 20 beds were viewed as optimal, in practice units typically ranged in size between 20 beds and 34 beds.

No generally accepted criteria have been developed for admission to special care units, although many accept only residents with irreversible dementia and problem behaviours and who have the ability to benefit from the program. In some facilities, residents remain in the special care unit as their dementia progresses and care needs increase,while in others, residents are discharged when for physical, cognitive or behavioral reasons they no longer benefit from the program.

Care strategies varied among 19 special care units studied in one survey, ranging from basic custodial care through to a focus on maintaining remaining abilities and enhancing quality of life. Physical exercise and music programs were rated as the most successful activities for residents with dementia.

The ratio of direct care staff to residents (day shift) in three surveys of special care units ranged from between 1:3 and 1:4 to between 1:7 and 1:12. Some units modify traditional assignments of tasks and others employ extra staff in the late afternoon and evening. Provision of training varies considerably.

Environmental design features also vary. For example, a survey of 26 special care facilities in the United States found 22 had increased security and visual access, 11 had introduced measures to increase orientation (ie., orientation boards and colour coding of corridors), nine had modified the communal space and seven had attempted measures to control noise.

The key cost components of specialized care are staff education, specialized therapy, and environmental modifications.

Many facilities lack the resources to establish special units and instead find ways of improving the quality of care provided to all residents within limited budgets. Examples from the literature include restructuring of staff management and program schedules, creation of in-house day programs, and modest environmental adaptations.

10.0 Legal and Ethical Issues

These issues arise when a resident with dementia must make decisions concerning finances or personal care and medical treatment. Arrangements for substitute decision-making concerning financial affairs can be made through the appointment of a trustee of the estate or through the use of an enduring power of attorney, where permissable. Arrangements for substitute decision-making for medical treatment is more problematic, particularly in provinces without effective legislation concerning guardianship of the person.

ACKNOWLEDGEMENTS

The administrators and staff members of Ontario's Homes for the Aged have made an invaluable contribution to this project. At the outset, the insights they provided during focus groups and site visits helped formulate the issues to be addressed in the project. They later spent many hours assembling and discussing the information requested in the questionnaire that serves as the foundation for this project. The high rate of response to the questionnaire attests to their professionalism and dedication to best care practices.

At various stages of the project we were assisted by Gloria Gutman, director of the Gerontology Research Centre at Simon Fraser University, and by Kim Lambert and Nadia Lambert, who provided the benefit of their years of experience in social research design.

The enthusiasm of team members from the Ministry of Community and Social Services has supported this project throughout its various phases. These members were: Joy King, Project Manager, Nursing Consultant/Senior Policy Analyst, Residential Services Branch; Shirley Cooper, Policy Analyst, Elderly Services Unit; James Edney, Medical Consultant, Residential Services Branch; Jane Henderson, Representative of Ontario Association of Non-Profit Homes and Services for Seniors; Sandy Knipfel, Manager, Residential Services Branch; Stanley Loo, Senior Research and Program Evaluation Analyst, Research and Program Evaluation; and Geoff Quirt, Director, Residential Services Branch.

1.0 INTRODUCTION

1.1 Terms of Reference

In 1989, the Residential Services Branch, Community Health and Support Division of Ontario's Ministry of Community and Social Services initiated a comprehensive study of care practices for residents with moderate or severe dementia in Ontario's Homes for the Aged. The terms of reference for the study identified two objectives:

- To describe and compare the range of strategies and techniques used for managing residents with dementia in Ontario's Homes for the Aged; and
- To describe, as a special focus, the role of the special care unit in caring for the elderly with dementia, the unique features of the special care unit, and the experiences in using special care units in Ontario's Homes for the Aged.

In order to meet these objectives, the Flett Consulting Group Inc., in partnership with Social Data Research Ltd., undertook a study drawing on a survey of general care practices for residents with dementia in Homes for the Aged in Ontario, a parallel survey of special care units within the Homes, and a review of the literature on care practices for elderly persons with dementia. This report, describing the results of the literature review, is Volume I of a three-volume study. Volume II describes general care practices and Volume III deals with special care units in Ontario's Homes for the Aged.

1.2 The Need for the Present Study

An increase in admissions of residents with dementia to Ontario's Homes for the Aged has been observed during recent years as a result of changing patterns of community-based and institutional care. In recognition of the increasing number of elderly persons in Ontario who are choosing to remain in the community rather than seek facility-based care, the Ministry of Community and Social Services has increased the number and range of services supporting seniors in their own homes or the homes of others. With the support of such programs as the Integrated Homemaker Program, the Alzheimer Community Program and the Home Support Program, increasing numbers of seniors are enabled to defer admission to long-term care facilities until the community-based programs can no longer meet their needs. Compared with seniors admitted to long-term care in the past, these seniors are more likely to have dementia and other health problems requiring assistance at the time they seek admission.

While home support has been helpful for elderly persons with mental health or physical health problems, it has been more effective for persons with physical health problems. Persons with mental health problems often have greater care needs, in many cases requiring continuous supervision. As a result, elderly persons with mental health problems seek facility-based care at a greater rate than persons with physical health problems.

The Ministry of Community and Social Services has recently adopted two measures to enhance the ability of Ontario's Homes for the Aged to care for residents with dementia. The first measure is a $100 million Capital Redevelopment Plan, which has two components: traditional renovations and community residential alternatives.

(1) Under the renovations component of the Capital Redevelopment Plan for Homes for the Aged, at least $66 million is allocated for traditional renovations of outdated facilities.

(2) Under the community residential alternatives component of the Capital Redevelopment Plan for Homes for the Aged, up to $33 million in capital and the necessary operating funds is provided for pilot tests of different types of residential service alternatives. Funding for community residential alternatives is aimed at enabling Homes for the Aged to test alternatives to facility care and increase their capacity in providing supported apartment living in the community.

In addition to the Capital Redevelopment Plan, the Ministry has also initiated this study of care practices in Homes as the foundation for the production and implementation of guidelines for caring for residents with dementia. These guidelines will be developed in consultation with the Homes and will be reviewed in practice, as subsequent phases of this project.

While the question of separate, special care units for residents with dementia has posed philosophical and practical issues in the field, it is not within the scope of this study to make recommendations on this issue or others. Rather, this study serves the larger project best by providing a clear description of current practices in Ontario's Homes for the Aged and on their special care units.

1.3 Organization of This Report

The balance of this report is presented in 10 main sections. Section 2 presents data from various studies concerning the proportion of residents with dementia in long-term care facilities and their demographic profile. Section 3 discusses philosophies of caring for residents with dementia that subsequently guide care practices, staff interactions with residents, and other aspects of the care environment. Care practices for residents with dementia are described in Section 4, with special reference to management of behaviours that are disturbing to others. Section 5 describes programs and services offered to residents with dementia. Staff and staff training to care for residents with dementia are discussed in Section 6. Section 7 provides an overview of some of the central considerations in environmental design for residents with dementia. Section 8 discusses the role of families and volunteers. Special care units for residents with dementia are discussed in Section 9, largely in terms of their major features as described in various surveys of such units. Section 10 addresses legal and ethical issues.

The methods used to research the literature are described in Appendix A. In order to identify relevant studies undertaken in other jurisdictions, letters were sent to ask for assistance from members of the Federal/Provincial/Territorial Sub-Committee on Long Term Care. Although none of the replies indicated development of guidelines for care of residents with dementia at the provincial or territorial level, or completion of surveys comparable to the survey of Homes for the Aged, they did indicate various policy activities which are summarized in Appendix B.

In this report, the term "residents with dementia" is used to describe residents of long-term care facilities who have Alzheimer's disease or other dementias. Authors of the literature discussed here use a variety of terms. For example, the Subcommittee on Institutional Program Guidelines for Health and Welfare Canada uses the term "elderly people with mental health problems" to describe persons aged 65 and older who have emotional, behavioural or cognitive problems and to include conditions such as dementia, depression, anxiety, and personality disorders (Health and Welfare Canada 1990). Descriptions of the literature provided in this report use the same terms as used in the source material, with the exception that the term "residents" and not "patients" is used consistently to describe residents of facilities.

The literature described here serves as a context for the findings of the survey of Ontario's Homes for the Aged. It is not intended to be a practical manual for practitioners or an exhaustive review of the subject areas covered, given the extent of the reported research in such areas as environmental design. Several documents have been used throughout this report. These documents include:

- Health and Welfare Canada. 1990. Report of the Subcommittee on Institutional Program Guidelines. Guidelines for establishing standards for services to elderly residents with mental health problems in long-term care facilities. Department of National Health and Welfare.

- Ministry of Community and Social Services. 1989. Dementia and activities of daily living. A report on technologies and environmental design that can assist people with Alzheimer disease and related dementias. Program Technology Branch. Ontario Ministry of Community and Social Services.

- Ontario Association of Homes for the Aged. 1985. Does it really matter if it's Tuesday? A guide to caring for the mentally impaired elderly. Ontario Association of Homes for the Aged. Willowdale, Ontario.

2.0 PROFILES OF LONG-TERM CARE FACILITIES AND THEIR RESIDENTS WITH DEMENTIA

2.1 Estimates of Mental Disorders in Long-Term Care Facilities

Demographic change in Canada and Ontario is resulting in an increase in the number of elderly persons in society and the number reaching an advanced age, who are more likely to develop a dementing illness. While the number of persons with dementia is estimated at about 33 per 1000 population for persons aged 70 to 74, it rises to about 117 per 1000 population aged 80 to 84 and about 220 per 1000 population aged 85 to 89 (Preston 1986).

Thirty years ago, most elderly persons with dementia received care in mental hospitals. Since the 1950s, the number of beds in psychiatric hospitals in Canada as a whole decreased dramatically, and elderly persons with dementia who require care now must obtain it from long-term care facilities (Health and Welfare Canada 1990). However, reviewing admissions data for Ontario, Rodenburg (1985) found no evidence that decreases in admissions of elderly persons to psychiatric hospitals resulted in increases in admissions to nursing homes and Homes for the Aged, and noted that some of these persons may have found care in chronic hospitals, rest homes and boarding homes for which no data are available. He found that during the period 1975 to 1981 the number of elderly persons admitted to psychiatric hospitals in Ontario decreased slightly while the rates of admission to nursing homes and Homes for the Aged remained fairly constant. The percentage of elderly residents in extended care beds increased, however.

Surveys of residents of long-term care facilities provide various estimates of the proportion with dementia and describe other aspects of the resident profile. These surveys and profile descriptions generally present group data describing residents of several facilities. The proportion of residents with dementia varies among facilities and changes over time within each facility as residents age. Also, demands on each facility to care for residents with dementia vary depending on the age of the population in its catchment area, the number of services and facilities available to serve this population, and the number of referrals each facility receives (Health and Welfare Canada 1990).

Studies of the prevalence of mental disorders among residents of long-term care facilities reviewed by Health and Welfare Canada (1990) found that between 52 and 94 percent of residents had psychiatric disorders (Exhibit 2.1). Organic mental disorders, primarily dementia, are the most prevalent and are a function of a transient or permanent dysfunction of the brain. Other mental disorders of residents in long-term care include depression (the most prevalent non-organic disorder), anxiety, adjustment disorders, and substance abuse.

Exhibit 2.1

Prevalence of Mental Disorders among Residents of Long-Term Care Facilities

Prevalence of Organic and Other Mental Disorders	Organic Mental Disorders	Other Mental Disorders	Reference
52%	30%	22%	Alberta Health (1988)
68%	39%	29%	Burns et al. (1988)
85%	46%	39%	Teeter et al. (1976)
94%	84%	10%	Rovner et al. (1986)

Health and Welfare Canada. 1990. Report of the Subcommittee on Institutional Program Guidelines. Guidelines for establishing standards for services to elderly residents with mental health problems in long-term care facilities. p.9

A survey of nursing homes in the United States, reporting data on 1.5 million residents, found that 42 percent of residents had some form of dementia, defined to include any chronic or organic brain syndrome. Fifty-eight percent had mental disorders, defined as dementia, depressive disorder, schizophrenia, other psychoses, anxiety disorder, personality or character disorder, and other mental disorders. The percentage of residents with dementia was lower in small facilities than in large facilities; 35 percent of residents in facilities with 49 or fewer beds had dementia, compared with 42 percent in facilities with 50 to 149 beds, and 45 percent in facilities with 150 or more beds (Agency for Health Care Policy and Research 1990).

Reviewing studies of the prevalence of psychiatric disorders among nursing home residents in the United States, Rovner and Rabins (1985) reported findings that mental disorders are frequently undiagnosed, misdiagnosed, or diagnosed in such a way as to obscure potentially treatable disorders. Although the exact prevalence of mental disorders among residents is not known, they said, it is likely that more than half of the residents have a significant psychiatric disorder.

The proportion of institutionalized elderly with severe disorientation in Ontario was estimated at 22 percent by Jeans et al. (1987). This estimate was based on a survey of a non-random sample of about 2400 residents assessed using the behaviour scale of the Multidimensional Observation Scale for Elderly Subjects (Helmes 1982; Helmes, Csapo, and Short 1985; Short 1982). The residents lived in seven continuing care and seven psychiatric hospitals, nine Homes for the Aged and 22 nursing homes in Ontario. The proportion of sample residents in psychiatric hospitals was larger than was the case for the institutionalized population as a whole, and the estimate was adjusted to reflect the proportion of residents in each type of facility in the province.

The OTA Task Force (1986) also reported on the prevalence of dementia in nursing homes based on assessment of residents. The task force reported that a 1983 study in Rhode Island which assessed residents using a cognitive rating scale found that 40 percent of residents under the age of 80 and 50 percent of those 80 years or older had dementia.

A survey that included 41 long-term care facilities in Metropolitan Toronto and the Region of Peel (nursing homes, Homes for the Aged and chronic care hospitals) obtained information about residents with irreversible dementia, assessed by staff observation of the residents. The survey found that on average, staff rated 43 percent of residents as having irreversible dementia. Of this group, 44 percent were rated as having severe irreversible dementia, 33 percent as having moderate dementia, and 23 percent as having mild dementia. In terms of age, 46 percent were aged 85 and older and 39 percent were aged 75 to 84. Seventy-eight percent of residents with irreversible dementia were female. Residents with irreversible dementia required considerable care, with 62 percent requiring heavy nursing care and 28 percent exhibiting disturbing or disruptive behaviour (MacFadgen 1987).

Facilities in the survey included 16 nursing homes, 16 Homes for the Aged, and 10 chronic care hospitals. Comparisons among the three types of facilities indicated that Homes for the Aged had a smaller proportion of residents rated as having irreversible dementia, with 11 Homes for the Aged reporting fewer than 40 percent of residents having irreversible dementia. Compared with the other facilities, Homes for the Aged reported more stringent admission criteria, with 53 percent refusing admission to persons with dementia while none of the nursing homes or chronic hospitals reported refusing admission.

Compared with the Homes for the Aged, the nursing homes were more likely to provide special programs (i.e., reality orientation) for residents with dementia and staff training on Alzheimer's disease. The Homes for the Aged were more likely than the nursing homes to report that their buildings were not designed or intended for residents with dementia and were more likely to identify a special unit for these residents as the environmental modification they would like to make (MacFadgen 1987).

Comparable proportions of all facilities reported that staffing meets special needs of persons with dementia to some extent (60 percent), and that additional assessment, supervision and special care are required (40 percent). The additional resources most needed to meet the needs of persons with irreversible dementias were beds for respite and short-stay care, home support services, and special care units or beds for long-term care (MacFadgen 1987).

2.2 Other Resident Profile Information

The Committee on Nursing Home Regulation in the United States found that residents formed two broad groups: "long stayers" unable to live in the community, who live in the facility for several months or years, and "short stayers", who typically are discharged from hospital and stay until death or discharge in a relatively brief period. A 1976 survey of residents of 107 nursing homes in 11 states in the United States found that 63 percent of new residents either died or were discharged within three months of admission. Residents who stayed longer accounted for most of the resident bed-days. About 70 percent of all residents on a particular day in all the nursing homes were still alive and in the same home 18 months later (Institute of Medicine, 1986).

The 1977 National Nursing Home Survey in the United States found that 70 percent of residents were 75 years of age or older, about 70 percent were female, and 12 percent had a living spouse (Institute of Medicine 1986). A 1987 survey of nursing homes in the United States, reporting data on 1.5 million residents, found 82 percent of residents were 75 years of age or older and 73 percent were female. More than half the residents (58 percent) were limited in four or five activities of daily living (ADLs); 20 percent were limited in two or three ADLs, and 11 percent were limited in only one ADL. Residents of larger facilities were limited in more ADLs than were residents of smaller facilities.

The percentage of residents limited in four or five ADLs was 34 percent in facilities of fewer than 49 beds, 56 percent in facilities of 50 to 99 beds, 66 percent in facilities of 100 to 149 beds, and 62 percent in facilities of 150 or more beds (Agency for Health Care Policy and Research 1990).

3.0 PHILOSOPHY OF CARE

The philosophy of caring for residents with dementia is described at several levels in the literature and in this report. The overall philosophy of care addresses environmental design, programming, staffing, the role of families, behaviour management and other aspects of the care environment that can be orchestrated to support the resident with dementia. More specific goals can be set for each of these components that complement the philosophy of care.

The Ontario Association of Homes for the Aged defines philosophy of care as a set of assumptions or values about a program and the people in it. It sets the tone for the program and reflects the view that staff will have of residents, their rights and the kind of treatment they are to receive. In this context, the Association wrote in its guide for caring for mentally impaired elderly persons that each resident is first and foremost a person and should be treated as a whole person, with needs for physical, social, emotional and spiritual well-being. Since caregivers cannot tell from moment to moment the extent to which a resident is in touch with reality, each resident should be treated as if he or she is in touch. Since residents are not always able to ask for the things they need, the environment must provide these things as if the resident were capable of asking for them.

The following are some examples of philosophy of care statements of the Association (Ontario Association of Homes for the Aged 1985, p. 17):

- Each human being is different and valuable no matter how disoriented. There is a reason behind all behaviour. The helper must use empathy to tune in to the reasons behind the behaviour.

- Rational thinking is not the "only" way. Feelings have a right to be expressed when rational thinking fades.

- We must be concerned with the care of the older person, emphasis being placed on prevention of disabilities intensified by the aging process, and the restoration of the resident to a level consistent with the limitation imposed by the aging process.

- Residents have the right to come to our setting and "live" rather than "exist" or come just as a place to die.

- Residents have the right as individual autonomous human beings with individual beliefs, feelings, memories and experiences to be treated with sensitivity to their special needs and those of their families.

- The environment should promote optimum opportunity for quality of life and quality care to all residents, recognizing each resident's unique needs and desired life-style.

The Subcommittee on Institutional Program Guidelines for Health and Welfare Canada summarized the philosophy underlying its guidelines for caring for residents with mental health problems in long-term care facilities as follows (Health and Welfare Canada 1990):

- Every resident is an individual with a full range of human needs and rights. Residents have a right to appropriate care, including environmental, recreational, therapeutic and other programs adapted to their needs. Behaviour that is disturbing to others may be reduced or more easily managed if underlying needs are understood and met.

- The long-term care institution is the resident's home. The environment should be as home-like as possible and adaptations should be made to overcome residents' deficiencies.

- The needs of each resident should be met through an individualized care plan which supports the resident's capacity for independence.

- Residents with different diagnoses share certain needs but do not always benefit from the same intervention.

- The staff require support, including adequate training, sufficient staff numbers, and opportunities to discuss their problems and successes.

- Families, significant others, and volunteers require support, including information, recognition, professional backup and encouragement.

In the United States, the Institute of Medicine Committee on Nursing Home Regulation found that the quality of life of nursing home residents was related to residents' sense of well-being, level of satisfaction with life, and feeling of self-worth and self-esteem. Quality of life includes satisfaction with the environment and the care received, accomplishment of desired goals, and control over one's life. Quality of life is enhanced by meaningful relationships, an environment that supports independence and includes personal belongings, and the opportunity to make decisions, even small decisions concerning clothing, meals and activities.

The committee also noted that nursing homes are the total environment for many residents until they die. Deficiencies in care, housekeeping or dietary services that could be tolerated during a brief hospital stay could become intolerable and harmful over a longer period (Institute of Medicine 1986).

4.0 CARE PRACTICES FOR RESIDENTS WITH DEMENTIA

4.1 Care Needs

What are the special care needs of residents with dementia? These residents have many of the same care needs as elderly persons who are cognitively normal, but in certain respects they have different needs arising from the symptoms of their disorder and their interactions with other persons. Their special needs are related to problem behaviours, such as wandering or aggression, competency to make decisions, functional deficits, psychotic symptoms such as hallucinations, and suffering related to depression and anxiety (Health and Welfare Canada 1990).

In other respects, the care needs of residents with dementia are much the same as those of other frail, elderly residents and are met through "best practices" of care. Mace (1987, p.13) writes:

> Most of these are not unique to the care of people with dementia, but apply to the care of all frail, ill individuals. However, both long term care providers and acute care providers sometimes fail to observe these practices.

Comprehensive assessment as the basis for individual care planning appears to be a cornerstone of good care practice (Health and Welfare Canada 1990; Ontario Association of Homes for the Aged 1985). The Institute of Medicine Committee on Nursing Home Regulation in the United States found that the three central requirements for providing high quality nursing home care are:

(1) a competently conducted, comprehensive assessment of each resident;

(2) development of a treatment plan that integrates the contributions of all the relevant nursing home staff, based on the assessment findings; and

(3) properly coordinated, competent, and conscientious execution of all aspects of the treatment plan (Institute of Medicine 1986, p.48).

The process of assessment, developing a treatment plan, and implementing the plan is described in some sources (Health and Welfare Canada 1990) as a problem-solving process that begins with identification of a resident's problems and then seeks interventions to address these problems. Other sources (Beck and Heacock 1988; Dawson et al. 1986) focus more on enabling the resident to function at maximum capability and preventing or reversing excess disability. Excess disability is defined as a reversible deficit that is more disabling than the primary disability. It occurs when the magnitude of the disturbance in functioning is greater than might be accounted for by the underlying illness. For example, a resident's inability to feed himself or herself would be an excess disability if the skill (part of long-term memory) could be re-activated through therapy. In many cases, the resident's cognitive impairment is viewed as the cause of the skill loss and therapy is not attempted (Dawson et al. 1986).

The need to treat the resident as a person with physical, emotional, cognitive and social dimensions is also inherent in the approach to care of residents with dementia (Beck and Heacock 1988). The goal of a holistic approach to resident care is implied in the multidisciplinary team approach, the comprehensive assessment, and the search for possible causes of disturbed behaviour in the medical, psychological, and social/environmental domains.

A detailed description of care practices that could be employed with residents with dementia is beyond the scope of this paper. Useful sources in this regard are:

- Edelson, J. and W. Lyons. 1985. Institutional care of the mentally impaired elderly. Agincourt, Ontario: MacMillan of Canada.

- Cornelia Beck and Patricia Heacock. 1988. Nursing interventions for patients with Alzheimer's disease. Nursing Clinics of North America 23:95-125.

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The balance of this section discusses admission procedures to long-term care in Ontario, assessment and ongoing evaluation, and the care plan. Management of behaviours disturbing to others is a central aspect of resident care and care planning and is discussed in terms of the prevalence of problem behaviours and their causes. The need to identify underlying causes and target strategies is illustrated in discussions of wandering and null behaviour, defined as lack of any observable behaviour or activity. Finally, the use of restraints is discussed briefly.

4.2 Admission Procedures

Procedures for accessing long-term care in Ontario vary in different parts of the province. Some communities use a placement coordination service while in others, each facility has its own admission committee. The Long-Term Care Task Force sponsored by the Ontario Ministry of Health and the Ontario Ministry of Community and Social Services is working towards development of a single-entry model of access to community-based services and long-term care. As part of this move, a standard schedule (including a mental health component) is being developed to determine individuals' service requirements. However, this schedule is not intended to guide a full assessment of the individual (OPGA 1990).

Rodenburg (1985) sees a strong need for comprehensive medical and psychosocial assessment to guide the long-term care placement of elderly persons with dementia in Ontario. Many elderly persons with mental health problems are admitted to hospital for evaluation, but little can be done for them there if the causes of the disorder cannot be treated. The individual may be incapable of living in the community, and the hospital is under considerable pressure to discharge the patient without careful planning. Application forms for nursing homes, Homes for the Aged and chronic care hospitals are completed indiscriminately, and all such facilities receive a mix of physically ill and mentally impaired residents (Rodenburg 1985).

While there is considerable discussion in the literature concerning admission criteria for special care units (discussed subsequently), little was found concerning admission criteria to long-term care generally. In a study of the system of care for persons with dementia in the Toronto and Peel regions, MacFadgen (1987) found the 16 Homes for the Aged in the sample reported more stringent admission criteria and lower proportions of residents with dementia than the 16 nursing homes in the sample. In a survey of 332 long-term care facilities in Minnesota, facilities with more than 100 beds had a significantly greater proportion of residents with dementia than did facilities with 100 or fewer beds (Hepburn et al. 1989). However, no connection was made to admission criteria.

4.3 Assessment and Ongoing Evaluation

In a series published by the National Council on Aging, Gayton broadly defined geriatric assessment as ". . . an approach to the problems of the elderly that, through prevention, planning and adaptation, aims to optimize the independence of the individual as she or he ages" (Gayton 1989, p.41). Health and Welfare Canada (1990) regards assessment as the first step in the care process, a systematic approach to problem solving. As stated above, assessment is used to identify problems in functioning and behaviour, and to search for the underlying causes of these problems in the medical, psychiatric and environmental/social domains. The resident's strengths are also assessed for their potential contribution to quality of life and as a means for overcoming problems. Promoting existing strengths reinforces the familiar and provides reassurance. It also provides the resident with a sense of competency and control (Dawson et al. 1986).

A comprehensive assessment usually is completed as part of the process for admission to a long-term care facility. Following admission, each facility usually conducts its own assessment as the basis for the preparation, application and evaluation of the individual care plan. The Ontario Association of Homes for the Aged (1985) suggest that this assessment be conducted by an interdisciplinary team and include:

- a comprehensive medical examination;
- a psychological profile;
- a mental status evaluation;
- a social/family history; and
- an assessment of ability to perform activities of daily living.

Dawson et al. (1986) suggest that the assessment identify specific competencies in self-care, abilities to communicate with each other, social abilities and interpretive ability (ability to derive meaning from words, objects and the environment). Strengths in these areas can be encouraged as part of the therapeutic care plan so as to prevent excess disability, reinforce the familiar, and foster a sense of individual competence. Much of the information needed for the assessment in some areas (e.g., self care) can be obtained through staff observation.

Structured assessment instruments and procedures may also be employed to assess self-care ability as well as cognitive ability and behaviour. For example, the assessment developed by Community Occupational Therapy Associates (COTA) in Toronto includes use of Lawton and Brody's scale for assessing activities of daily living (Lawton and Brody 1969) and the Folstein Mini-Mental State Examination for assessing cognitive ability (Folstein, Folstein, and McHugh 1975). This non-profit organization, which provides assessment services to Homes for the Aged, nursing homes and other clients, also includes in its assessment testing for the presence of diagnostic criteria for dementia, a family history, a medical history, environmental safety, and a scale for detecting depression (now under review) (OPGA 1990).

A behavioural assessment supplement has been added to the application/assessment for personal home care placement. Developed by the Manitoba Health Services Commission, the supplement responds to concerns that the larger assessment does not provide an accurate or complete picture of persons with behaviour problems. The supplement, used at the discretion of home administrators during pre-admission, has two main sections. The first comprises 18 questions concerning behaviour, such as confusion in familiar places, withdrawal, and suspicion, the date of onset, examples of the behaviour (if exhibited), and current management. The second section collects information on family dynamics, interpersonal relationships, education and occupational history, personality profile and coping skills, community involvement, and history of any mental illness. This information is to be used in planning the approach to care. For example, relationships meaningful to the resident could be fostered to promote adjustment to placement in the home.

McCracken and Fitzwater (1989) discuss how a behaviour scale is used in a long-term care facility to guide initial placement of residents with dementia on either an open or a closed unit. After an initial screening, the scale is administered monthly and is used in conjunction with observations and interviews to monitor the resident's condition. The scale has also been useful in pinpointing functional areas in need of support and identifying sudden changes in the resident's condition that signal problems with prescribed drugs or the onset of a new pathology. The scale employed by the facility is the Haycox Dementia Behaviour Scale, which defines seven ratings in each of the following areas: language/conversation, social interaction, attention/awareness, spatial orientation, motor coordination, bowel and bladder, eating and nutrition, and dressing and grooming (Haycox 1984).

Ludwick (1981) describes a tool used in acute care and chronic care facilities to determine the extent and nature of behaviour otherwise classified generally as "confusion" or "disorientation". A more accurate description of the confusion or disorientation helps nursing staff assess mental status and select the most appropriate interventions, and provides a baseline for assessing subsequent changes in the resident's condition. The Confusion Assessment Tool (Ludwick 1981) assesses the individual's abilities in nine areas, including orientation to time (month, day or date, time of day) and place (name of hospital, location within hospital); self-identity (names family members, identifies self); ability to follow instructions (deep breathes, turns and coughs on command, moves extremities); recent memory (describes last meal) and intermediate/long-term memory (states doctor's name, present or past place of employment).

After the initial assessment, ongoing evaluations monitor any changes in the resident's functional abilities and provide a basis for adjustments to the care plan. The Ontario Association of Homes for the Aged (1985) suggests evaluations be made one month after admission to the unit to determine whether adjustments to the care plan are necessary, and three months after admission to determine how the program has affected the resident's functioning and whether any changes in the care plan are necessary. Subsequent evaluations would be made at any time if behaviour changes occur and otherwise at regular intervals, depending on the resident's level of functioning. Residents at the highest level of functioning could be evaluated every three months and residents at the lowest level of functioning, the most severely impaired, every 12 months.

The resident monitoring process and schedule for evaluation are included in the care plan. Some interventions, such as medications, may require continuous monitoring. Formal re-evaluations should be made during a team meeting. Participants should consider whether the facility is continuing to meet the residents' needs or whether the resident should be discharged to a more appropriate facility (Health and Welfare Canada 1990).

4.4 The Care Plan

The care plan is a written description of the resident's problems and needs, goals or expected outcomes of care, interventions to be used to meet these goals, and responsibilities for carrying out interventions. It allows for continuity of care among caregivers and becomes the focus for interdisciplinary collaboration (Health and Welfare Canada 1990).

A team meeting may be the best venue for formulating a care plan because group discussion is an effective way to identify the full range of a residents' problems and the underlying causes of these problems. Interventions can be selected from a broad perspective and responsibilities can be assigned efficiently during the meeting. Participation in preparation of the plan gives team members a strong commitment to implementing it (Health and Welfare Canada 1990).

Frequent interdisciplinary meetings to discuss and adjust care plans help develop consistency in interventions. They are also important in identifying problem behaviours, their causes, and possible strategies for managing them.

4.5 Approaches to Behaviour Management

4.5.1 Prevalence of problem behaviours

The literature provides various estimates of the percentage of residents with dementia that wander or have behaviours disturbing to others. A survey of elderly persons with irreversible dementia in Toronto and Peel Region found that 21 percent of these persons in acute care and 28 percent in long-term care had disturbing or disruptive behaviour, compared with 44 percent of these persons receiving care through community services (MacFadgen 1987). The larger percentage with disturbing behaviour reported by community services may reflect the community services' lower acceptance of the individuals' behaviour, the authors said.

Another estimate of the prevalence of disturbing behaviour is provided in a survey cited by McCartney et al. (1987). The survey found that of 3,456 residents in 42 skilled nursing facilities, 64.2 percent (2218) had significant behaviour problems and of these, 11.5 percent (257) had serious problems (Zimmer, Watson, and Treat 1984).

Noise-making was a problem behaviour attributed to 29.0 percent and 31.1 percent of residents of two long-term care facilities in Toronto (Ryan et al. 1988).

A random sample of nursing home residents in the United States, assessed using a behaviour rating scale, found that 40 percent had communications problems, 38 percent had delusions or hallucinations, 38 percent were restless, 38 percent were passive-aggressive, 36 percent were demanding, 36 percent were socially objectionable, 34 percent were disruptive, 26 percent were aggressive, 24 percent wandered, 24 percent were noisy, and 14 percent were self-destructive. The authors (Rovner et al. 1986 as cited in Hoffman, Platt, and Barry 1987) believed that the hallucinations and delusions that often accompany dementia were the underlying cause of much of the problem. Hoffman, Platt, and Barry (1987) commented that residents' difficulties in expressing needs and ideas and in understanding the conversations of others was frustrating for both staff and residents, and often resulted in emotional outbursts by residents.

A survey of nursing homes in the United States that provided data on 1.5 million residents found 31 percent yelled or became upset, 11 percent wandered, and 11 percent physically hurt others. A larger percentage of men than women had these behaviours, particularly hurting others. Sixteen percent of men physically hurt others, compared with 9 percent of women; 33 percent of men yelled or became upset, compared with 30 percent of women; and 12 percent of men wandered, compared with 11 percent of women. Wandering appeared to increase with age, reported for 9 percent of residents aged 65 to 74, 12 percent aged 75 to 84, and 15 percent aged 85 to 89, but decreasing to 10 percent for residents aged 90 and older. The percentage of residents that yelled or became upset was greatest for residents aged 65 to 74 (36 percent) but did not decrease uniformly with age. The percentage that physically hurt others decreased uniformly with age, from 14 percent aged 65 to 74 to 9 percent aged 90 and older (Agency for Health Care Policy and Research 1990).

A few studies based on small samples reviewed by Gutman (1989) found persons with dementia in a nursing home and in a day program setting remained quietly seated for much of the day. In observations of eight nursing home residents with dementia, Milke et al. (1987) found the residents spent one third of their time in inactive sitting or standing. Similarly, observations of four participants in a day program for persons with Alzheimer's disease found that other than walking to the dining room or to the bathroom, the participants remained seated most of the time, napping or clasping their hands (Shroyer, Hutton, and Anderson 1987). Dobbs and Rule (1988) found that persons with dementia were quiet 81 percent to 86 percent of the time.

Regardless of the prevalence of disturbing behaviours among residents of long-term care facilities, behaviour and behaviour management is a central issue in the care of these residents. When asked about their concerns about caring for residents with dementia, 58 percent of respondents to a survey of 332 nursing homes in Minnesota identified management of resident behaviour, followed by 37 percent concerned about environment and such aspects as security and space for wandering (Hepburn et al. 1989).

4.5.2 Identifying problem behaviours

As part of the care planning process, staff must be careful in identifying a behaviour as a problem. The Ontario Association of Homes for the Aged (1985) suggests that staff ask, "Whose problem is it? Is it a staff problem or a resident problem?"

Similarly, Health and Welfare Canada (1990) suggests that problems be considered within their context. Wandering may be a problem if residents can stray onto a busy street, but may not be a problem in a secure area. Some behaviors, such as incessant questioning, may be a problem to some staff but not to others, and some behaviours are viewed as problems because staff have inappropriate expectations. For example, sexual behaviour among residents with dementia often mobilizes the paternalistic tendencies of staff and staff intervention, with little attempt to determine whether the residents involved are capable of informed consent or to recognize the human needs of both partners (McCartney et al. 1987).

4.5.3 Causes of problem behaviours

Most behaviour problems occur for explainable reasons and should not be regarded as an inevitable part of the disease process. While knowledge of the stages of Alzheimer's disease and other dementias may be useful in diagnosis, a caregiving focus on staging of the disease may lead staff to regard development of a new behaviour as an untreatable adjunct of that particular stage rather than as a signal for reassessment. A problem-solving approach to behaviour looks instead for the underlying medical, psychiatric, and environmental/social causes of the problem and seeks targeted solutions addressing one or more underlying causes (Health and Welfare Canada 1990; Orr 1986).

Orr (1986) describes behavioural problem solving, a series of steps leading to strategies for controlling problem behaviour. As a first step, nurses and nursing assistants on all shifts document the problem behaviour for at least two days (and preferably one week), maintaining detailed records of events before and after the behaviour occurred and the strategy used to resolve the situation. Although only one behaviour at a time is observed, records are likely to indicate interrelated behaviours and patterns of behaviour. Once the behaviour has been fully documented, the interdisciplinary team discusses the advantages and disadvantages of possible interventions and selects one to be employed by staff on all shifts. The use of this intervention is well documented so that staff can learn which interventions work and which do not.

Problem behaviours may have one or more medical, psychiatric or social/environmental causes. Medical and psychiatric causes may be disclosed by a psychogeriatric assessment. Such assessments found medical and psychiatric causes for the disturbed behaviour of about 45 percent of patients with dementia who were admitted to an acute psychogeriatric assessment and treatment centre in Australia because of their behaviour (O'Connor 1987). Of the 70 patients assessed, 34.4 percent had a significant untreated physical illness, 8.5 percent had drug-induced toxicity, and 11.4 percent had a superimposed psychiatric illness. Progressive dementia alone was believed to be the cause of the behaviour in 39 percent of the residents.

Also, 43 percent of patients were found to have had significant premorbid personality problems, such as a tendency to temper outbursts or an anxious personality. These problems may have contributed to the behavioural disturbance, because dementia is marked by exaggeration of premorbid personality traits (O'Connor 1987).

Problem behaviours in many cases are a response to the environment, usually defined broadly. Hiatt (1987) identifies four aspects of the environment:

- the physical environment, including sights, sounds, textures, temperatures, air quality, space and objects;
- the social environment of people and their numbers, roles and characteristics;
- the psychological environment, comprising mental concepts of reality, including mental images (e.g. routes or relationships) and preferences (e.g. reactions to colour);
- norms and patterns established in daily routines and caregiving activities.

Some or all of these may be manipulated to manage behaviour.

"Treat the treatable" and "correct the cause" are important principles for intervention. Treating social withdrawal through attendance at activity programs will be ineffective if the withdrawal is a symptom of a treatable depression. Also, interventions must be planned with an understanding that some problems can stem from several possible causes that differ among individuals. For example, sleep disorders may arise from depression, pain, fear or a too-early bedtime. Also, one underlying cause can create many problems; for example, fear may result in aggression, withdrawal or depression (Health and Welfare Canada 1990).

4.5.4 Examples of behaviour management

Several examples in the literature underscore the need to identify the underlying causes of behaviours so that effective interventions can be attempted in several spheres. For example, Calkins (1987) suggests attention to both the physical and social environments to counter null behaviour among residents. Such behaviour is most prevalent when residents do not have the opportunity to choose between privacy and socializing, and when environments provide too much or too little information.

To counter null behaviour, opportunities for formal and informal socialization must be provided. Simple strategies include placing chairs at right angles to encourage conversation, rather than lining them up along the walls. Groupings should accommodate no more than four to six persons and provide a view to the nursing station or some other interesting view. Seating areas in nooks along corridors can be created to allow opportunities for informal socialization or private time alone if most bedrooms are shared. Privacy can also be fostered by institutional norms and patterns, for example by staff practices with residents in the bathroom and during bathing. A routine knock on the door before entering a resident's room signals respect for privacy.

Wandering may have different underlying causes and may manifest itself differently. Research reviewed by Beck and Heacock (1988) identified different patterns of wandering as well as psychological factors that influence the tendency to wander. The tendency to wander may be associated with a lifelong response to stress by walking, a need for security, or industriousness amplified by work roles. Wanderers may have been more physically active in their leisure and work roles than were non-wanderers.

Wandering, as well as confusion and aggression, is also described as agenda behaviour, behaviour that includes the verbal and non-verbal actions residents with dementia use in an effort to fulfill their felt social, physical and emotional needs. The source of the behaviour is fear engendered by separation from the people and environments that made the resident feel comfortable, frustration when the resident's agenda is thwarted by staff, and the resident's need to be needed (Rader, Doan, and Schwab 1985).

Staff response to wandering depends on how the problem is conceptualized. Staff response to wandering as an agenda behaviour identifies the underlying emotions, acknowledges them to the resident, and provides reassurance. If agenda behaviour is allowed to run its course rather than being suppressed, it can be diminished or even eliminated as residents develop consistent feelings of safety in their environment (Rader, Doan, and Schwab 1985).

Wandering viewed as a lifelong response to stress, as industrious behaviour or as a need for physical activity requires provision of appropriate outlets. Structured physical exercise may serve some needs, while assigned tasks such as sweeping or dusting may have more meaning for others. A safe environment for wandering can serve many needs and safety and security measures can be implemented (Beck and Heacock 1988).

4.6 Use of Restraints

Chemical and physical restraints can be used to manage disruptive behaviours such as wandering, noisiness, trespassing, and aggressiveness. Physical restraints include any appliance used to inhibit free physical movement, and include an attached lap-top table that prevents residents from rising from a chair, locked doors, and tying a resident's wheelchair to a bedrail. Chemical restraints are drugs used solely to inhibit a behaviour or movement (Health and Welfare Canada 1990).

Orr (1986) maintains that while restraints for posture support and medications have appropriate roles in long-term care, chemical and physical restraints on behaviour reflect poorly on the quality of care provided. Restraints reduce residents' dignity. They also increase care needs, as they make residents more dependent and difficult to manage. Increasingly, families who manage their relative at home without the use of restraints expect that long-term care facilities will be able to do so also.

Although no data are available on the use of restraints, some indicators suggest it is fairly widespread. For example, Hiatt (1987) found 82 percent of institutions use body holders or geriatric wheelchairs to manage wandering, and Hepburn et al. (1989) found restrictive measures were used in most of the 332 nursing homes they surveyed in Minnesota.

In some cases, use of restraints may pose greater dangers than the wandering, risk of falls, or other behaviour they are being used to prevent. Hiatt (1987) proposes several strategies for reducing the use of restraints, including the following:

- minimize environmental hazards related to falling, such as poor lighting and obstacles in passageways;
- re-evaluate medications and their contribution to the risk of falling;
- consult family members for possible underlying reasons for the disturbing behaviour;
- provide sturdy chairs, platform rockers, and wheelchairs designed to meet the needs of elderly persons; and
- develop bodily strength through exercise programs, including chair exercise.

Other measures for reducing the use of restraints proposed by Hiatt (1987) pertain to standard practices for the use of restraints as described in Ontario Association of Homes for the Aged (1985) and Health and Welfare Canada (1990). As a standard practice, each facility should develop a written policy on the use of restraints, and this policy should be circulated among staff and explained to family members. Restraints should be used sparingly, with extreme caution, after other measures such as individual, one-to-one contact fail to calm the resident. The order for restraints should be given by the resident's physician or the facility's medical director and written into the resident's chart. Usually one to three days is sufficient for an initial order, with review after that time. Standing orders should be reviewed monthly. A model for policy on the use of restraints and alternatives in long-term care facilities has been developed by the Ontario Association of Non-Profit Homes and Services for Seniors (1990).

5.0 PROGRAMS AND SERVICES FOR RESIDENTS WITH DEMENTIA

5.1 Program Goals

"Programs is an all-encompassing word which describes what residents do during the day," according to the Ontario Association of Homes for the Aged (1985). It includes all aspects of the residents' day and all activities, including the recreational and therapeutic activities which typically are scheduled a few times during the day, as well as daily living and housekeeping activities. The program provides structure to the resident's day and includes periods for unstructured and informal activities. Programs are developed in response to the facility's philosophy of care and the strengths and needs of residents as identified in individual care plans (Ontario Association of Homes for the Aged 1985).

Examples from the literature illustrate how program goals reflect statements that can be included in a facility's philosophy of care. For example, a philosophy and complementary program goal is to provide residents with a life as close as possible to the one they lived before moving to the facility. This goal suggests a certain approach to various activities, including mealtimes. Since most people in their own homes eat at tables with complete, individual place settings, the program for meals in a facility should follow this pattern as closely as possible while adapting it for individual capabilities and preferences (Ontario Association of Homes for the Aged 1985).

Aasen (1987) provides examples of how opportunities for personal control and decision-making, which can be included in the philosophy of care, can be enhanced as part of the daily program. For example, residents can be offered opportunities to participate (or to decline to participate) in activities that reflect their personal talents, values or interests. A resident with an interest in music can be offered various musical experiences within the range of choice that is comfortable for him or her. In this case, both the resident's need for control and decision-making and his or her interests and values would be recorded in the care plan, with the program following from the plan.

In reviewing the literature on various programs and approaches for residents with dementia, Zarit and Anthony (1986) found that goals of interventions are frequently described in terms of changes in mood or activity levels among participants. Such goals are inappropriate because they may reflect only the desires of staff and family, and may fail to consider the residents' condition or wishes. Also, changes in mood or activity should not be considered as ends in themselves but as part of a larger plan of resident care.

An appropriate goal for programs and services for residents with dementia could be to help them function at as high a level as possible, given the underlying brain damage. This goal implies limiting excess disabilities, defined as impairments in everyday functioning that are worse than expected, considering the underlying biological deficits. Related goals are to enable residents to maintain as much control as possible in decisions about how to lead their lives and to maintain pre-existing habits, values and preferences for as long as possible (Zarit and Anthony 1986).

5.2 Programs and Individual Care Planning

There seems to be general agreement in the literature that individual and group programs should be designed to reflect individual residents' abilities and needs as identified in the care plan (Aasen 1987; Griffin and Matthews 1986; Health and Welfare Canada 1990; Ontario Association of Homes for the Aged 1985). A description of practices in the special care unit at the Bethany Care Centre in Calgary, Alberta illustrates this approach (Rohs 1986).

New admissions to the unit are assessed to determine their level of functioning, physiological needs, need for security, and any other needs identified by the multidisciplinary team. A team conference is held to review the assessment, determine the individual's level of functioning, and prepare the care plan. The plan addresses three aspects of activities of daily living: basic care activities, such as bathing, dressing, grooming, and any special physiotherapy treatments needed; dining activities, including regular meals and special events with family members; and recreational/diversional activities that provide interaction with people to meet psychosocial needs. Each resident is assessed at one of four levels of functioning, to help nursing staff be realistic in goal setting. Care plans are reviewed once each month. Individuals who have shown improvement are assigned activities suitable for a higher level of functioning, while individuals who are not coping well are assigned less demanding activities.

The London Psychogeriatric Rating Scale (Hersch, Kral, and Palmer 1978) is used to provide objectivity and formulate more accurate care plans. The scale, which assesses mental disorganization/confusion, physical disability, socially irritating behaviour, and lack of involvement (disengagement), is administered two weeks after admission and then every three months. The on-going evaluations are used in re-assessing the individual's level of functioning.

Continuing evaluation is important in planning care and selecting activities. Depending on the type of dementia experienced by the resident, deterioration may be progressive or may occur as a stepwise decline which allows the resident to function at a certain level for a period of time. In either case, goals set beyond the resident's capabilities will lead to agitated behaviour and upset the resident, and should be adjusted accordingly (Griffin and Matthews 1986).

Within the context of the care plan, programs should be assessed to determine whether they are addressing some negative effect of other treatment or the environment generally, as evinced in apathy or withdrawal. If so, the program is probably not benefiting the resident more than any measures that could be taken to address the basic problem directly (Zarit and Anthony 1986).

5.3 Other Considerations in Programming

The approach to activities can be more important than the activities themselves. An approach that adapts activities to residents' needs and proceeds at their pace without undue pressure creates confidence, security and trust (Zachary 1984). At Wesley Hall, a demonstration project in Michigan for persons with dementia, staff found the approach they use will usually make a difference in their success or failure with an individual in any situation. The most successful approaches were versatile and included gentle cajoling, affectionate encouragement, diversion, humour, withdrawing and returning later to try again, giving the resident time to think and respond, and varying the introduction of a topic or activity that may trigger resistance (Coons and Weaverdyck 1986).

Health and Welfare Canada (1990) and Ontario Association of Homes for the Aged (1985) identify several issues that should be included in planning a program of activities:

- Activities should offer a reasonable chance of success and be geared to the residents' physical, sensory, cognitive, emotional and perceptual abilities.

- Residents with different levels of impairment should be able to participate differently in any given program component.

- Group and individual activities should be offered.

- Participation of family members and volunteers should be encouraged.

- There should be opportunities to participate in activities away from the unit.

- Programs are the medium for interactions between residents and other persons, and they should therefore be designed so as to maximize the quality of these interactions.

5.4 Individual and Group Programs

Residents with dementia often fail to benefit from group programs planned for the general population of a long-term care facility. While individual, one-to-one programs can be tailored to these residents' needs, most facilities do not have the staff or resources to provide such programs extensively (Lindsey and Szumski 1988; Maloney and Daily 1986).
Griffin and Matthews (1986) describe the benefits of individual treatment and group programs for residents with dementia. Individual treatment provides the resident with personalized, direct attention that can respond immediately to the resident's changing moods. A feeling of warmth and understanding can be conveyed more readily on a one-to-one basis and nuances in communication can be detected that could be lost in a group situation. A therapist needs time alone with a resident to establish initial rapport and then identify problem areas for further therapy.

Group treatment can be beneficial in that it can provide a primary reference group, one in which participants develop a sense of trust and acceptance. Such feelings encourage them to perform at their highest level of functioning. The approval and disapproval of the group also encourage improvements in behaviour, and group treatment allows for repetition of an activity that each member is learning.

Lindsey and Szumski (1988) and Maloney and Daily (1986) describe group programs for residents with dementia with several components or approaches. Maloney and Daily (1986) describe a program at the Jewish Home for the Aged in San Francisco for residents who appeared unable to benefit from other programs in the home. The residents were divided according to their level of functioning into two groups of six that met three times each week for up to 45 minutes. The sessions were used as vehicles for reminiscing, remotivation therapy, and sensory stimulation and sensory integration. Reality orientation was not emphasized, although orienting information was provided if residents asked for it. Remotivation therapy was adapted to provide a structure to each meeting, which began with greetings followed by introduction and discussion of sensory stimulation objects selected to convey a theme.

Lindsey and Szumski (1988) describe a remotivation program instituted in six affiliated nursing homes in Florida. They note that remotivation therapy "enhances rehabilitation efforts by focussing on the emotional aspects of treating residents who seem to have lost the will to be involved and who need support to function" (p.14). The program was structured around five activities. A grooming class was developed to improve self esteem and increase interest in personal appearance. A sensory stimulation group was developed for lower-functioning residents to improve or maintain their level of awareness. A diner's club was formed to encourage more residents to eat in the dining room and to increase their socialization. An adapted remotivation group was formed to increase communication, attention span and social integration. Finally, individualized, one-to-one visits were planned for residents who were unable to leave their rooms.

Remotivation aides were recruited from each facility's current staff and received three one-day training sessions. A system for aides to share program ideas was also developed. The activities were introduced one at a time over five weeks. Participants were selected by a care planning team and their progress was monitored through care conferences. The cost of each facility's program was less than $15,000 for the first year and included equipment purchases, wages and benefits, and training. Remotivation aides spent 30 hours of the weekly 40-hour shift in direct contact with residents, and used the remaining 10 hours for preparation, consultation and documentation.

Most of the program participants (57 percent) showed improvement in self-care, increased social interaction, and increased feelings of self-esteem and usefulness. Seven per cent of showed deterioration and 36 percent remained stable.

The authors recommend that the activities described above be provided on a program basis, rather than as part of a larger group of activities. The program approach allows for a focus on a small group of residents, team involvement, organized follow-through, a system of recognizing and responding to changes in residents' functioning, accountability among staff, and long-term consistency. While the recreation director had tried in the past to offer similar programs for residents with dementia, too often the schedule was disrupted by unscheduled administrative meetings or an absence or shortage of volunteers (Lindsey and Szumski 1988).

5.5 Reality Orientation

In theory, reality orientation reactivates potentially usable parts of the brain or develops new ways of functioning to compensate for brain damage by continually orienting residents to the environment and by placing them in a group situation where they meet and compete with others. Reality orientation can be presented in a 24-hour approach and in a classroom approach. The latter comprises 30-minute daily sessions in which participants are oriented to date, time and place, and other information is presented. Twenty-four hour orientation entails the introduction of orienting information into casual exchanges between staff and residents (Gutman 1989). Gutman (1989) reviewed a number of studies of the efficacy of either approach, using control groups and structured instruments to measure change, and found the results were conflicting and inconsistent. Similarly, Zarit and Anthony (1986) found the results of reality orientation studies equivocal, given the inconsistency of findings and methodological difficulties. These authors question whether reality orientation serves the needs of residents or of staff members. They cite a case in which a resident was happy and cooperative until she joined a reality orientation group and became unhappy at learning that she lived in a nursing home.

The Ontario Association of Homes for the Aged (1985) suggests that reality orientation be made an intrinsic component of daily care and that such an approach will do away with the need for classroom sessions.

Reality orientation is used by all staff members at the Maimonides Hospital and Home for the Aged in Montreal as a means of reassuring anxious and confused residents. Often, residents with dementia are aware that they do not know their name, where they are or who their friends and relatives might be. This awareness creates fear and anxiety that can only be allayed by appropriate information. Since residents are unable to remember this information, it must be repeated as often as necessary. In time, residents recognize that they are among friends who will help them when they are confused (Novick 1982).

5.6 Effectiveness of Interventions

Not enough is known about the outcomes or effects of programs and services for persons with dementia to generalize about effective interventions (Zarit and Anthony 1986; Mace 1987). There is little agreement on appropriate goals for interventions with persons with dementia, and inadequate instruments for assessing subtle changes in behaviour or other outcomes. Most studies of interventions lack adequate controls, sufficiently large samples, and follow-up studies to determine whether therapeutic gains are maintained. Also, not enough is known about behaviours at each stage of the various dementing illnesses to assess whether an intervention has effectively changed a behaviour. For example, if caregivers do not know the percentage of persons with a particular illness that are likely to wander or be aggressive, it is difficult to determine whether any intervention has reduced that behaviour.

Improvements most frequently reported in the literature entail removal of excess disability and improvement in social functioning. Reports of such improvements in response to changes in residents' physical or psychosocial environment support the view that residents are very vulnerable to their environment and therefore more responsive to improvements. "It is therefore worthwhile to attempt to define the best possible care for people with dementing illnesses and to identify the factors that make life as satisfactory as possible for them" (Mace 1987, 13).

6.0 STAFF AND STAFF TRAINING

6.1 Staff Issues

Staff training was the central concern of much of the literature reviewed here concerning staff and the care of residents with dementia. Other issue areas, such as the type and number of staff needed and staff supports, received less attention.

There seemed to be general agreement on the need for a multidisciplinary care team to respond to the complex nature of the problems experienced by residents with dementia (Gutman 1989). The care team can include both persons drawn from within the facility and from outside sources as needed (Health and Welfare Canada 1990). The team should also be multi-level, tapping the experiences of staff at different levels of each department and providing them with information and advice as needed on the care of each resident. Since the attendance of all staff at meetings would be unwieldy, meetings could be conducted by a core team, with periodic participation of others and with results communicated to others by various means (Ontario Association of Homes for the Aged 1985).

Although rotating staff on units caring for residents with dementia has been described as a means of relieving stress among staff (discussed in Section 9.0), the Ontario Association of Homes for the Aged (1985) presents several arguments for permanent staffing. Permanent staffing provides greater continuity and stability for residents with dementia, and reduces their confusion. It allows for greater liaison between staff on the unit and volunteers, family members and staff on other units. Permanent staff are more likely to become involved in program planning, accept responsibility, and follow through on issues. They have a longer period of time to assess residents and develop strategies for managing behaviour. Positive group dynamics are easier to develop.

Since both staff and administration may be uncomfortable with permanent assignment, an initial six-month commitment by both parties allows staff to become familiar with the residents and to develop skills, and allows administration enough time to assess staff members' suitability. After the six-month period, both parties can decide whether to continue the assignment (Ontario Association of Homes for the Aged 1985).

While training is a recognized qualification, several sources also mentioned the importance of personal characteristics. While hiring for Wesley Hall, a demonstration project in Michigan for persons with dementia, the following traits were considered important: flexibility, sense of humour, patience, willingness to be part of a team, and good communications skills (Coons 1987). Staff recruited to a special care unit described by Peppard (1985, 1986) as cited in Gutman (1989) were chosen in part for proficiency in their present duties, calmness, resilient personality, creative ability to act appropriately even during a resident's catastrophic reaction, and good interpersonal skills.

The Ontario Association of Homes for the Aged (1985) notes that although staff find it rewarding to work with residents with dementia, they require support. This support can be provided in many ways. For example, staff need an opportunity and a mechanism to discuss problems on the job, feedback on how their input and requests are being handled, appropriate physical supports and aids used in resident care, and regular in-service training responsive to staff needs and desires for education on particular topics.

6.2 Staff Training

Special training for staff caring for residents with dementia is as important as physical design and the opportunities made available to residents for continuing involvement in the world around them. Without special staff training on maintaining a therapeutic milieu, new programs and facilities designed for residents with dementia will be no more likely to meet these residents' needs than are many established facilities (Coons 1987). Responsibility for maintaining the therapeutic milieu is largely the responsibility of non-professional front-line staff who frequently receive little or no training. Although staff may attempt a variety of tactics in managing residents they find difficult, such encounters often leave them feeling frustrated and depressed (Hoffman, Platt, and Barry 1987).

The components of education within the long-term care facility are basic training and continuing education comprising an orientation program, orientation review and evaluation of the orientation program, and in-service and external continuing education (Health and Welfare Canada 1990). Principles of adult learning, such as active involvement in solving problems relevant to the work environment and opportunities to ask questions and disagree, should be considered in developing the program (Canar and Johnson 1986; Health and Welfare Canada 1990).

Possible methods of training include lectures and supplementary audiovisual material, two of the most frequently used methods of training nursing home staff. Role playing emphasizes relationships, interactions and feelings. Journal-keeping allows staff to reflect on their experiences and encourages accurate observation of their own behaviour and residents' behaviour. Staff exchanges between facilities can introduce staff to new procedures and a resource centre shared by several facilities could be established (Coons 1987; Health and Welfare Canada 1990).

In terms of content, six issue areas were identified by the Ontario Association of Homes for the Aged (1985):

- identifying residents' needs on an ongoing basis;
- training that helps staff see the potential for growth in residents with dementia;
- fire drill plans and emergency procedures for residents with dementia;
- procedures that enable staff from one discipline to share information with staff from another discipline;
- the role of residents' families; and
- the potential contribution of volunteers.

Other subject areas suggested by Health and Welfare Canada (1990) include normal aging and changes in body systems, assessment and treatment of mental disorders in the elderly, the role of independence in maintaining self-esteem, behaviour management strategies, and the role of social networks in the health of older adults.

Training methods designed for Wesley Hall were intended to help staff discard the role of caretaker and develop roles as enablers, helpers, and friends (Coons 1987). Specific training objectives were to change many of the negative attitudes staff held concerning residents with dementia, increase staff members' repertoire of approaches, improve staff skills in helping residents function independently, and develop a cohesive staff team. In order to change staff attitudes to individual residents who had been difficult to work with previously on other units, staff were asked to list the strengths and needs of these residents. This exercise gave staff a new perspective on each resident and presented new ways of approaching them. The exercise was used regularly at Wesley Hall, particularly when difficulties were encountered with individual residents.

Training to increase staff members' repertoire of approaches required them to abandon some they used in other areas of the nursing home in favour of approaches that could be adapted to individual needs or moods of the moment. Control and condescension, and the feelings they create, were explored in role playing and group discussion. New approaches were tested and although none worked consistently well all the time, the approaches that were most effective were touch, verbal reassurance, humour and diversion.

Task breakdown developed by occupational and physical therapists was taught to staff so that they could help residents function to their best ability. Staff learned to recognize the steps involved in any task, which steps each resident could perform, and the type of help needed by each resident to complete a step or series of steps.

Training related to team building included experiential exercises in cooperation, in giving and receiving feedback, and in problem solving techniques. Weekly staff meetings were used for training, for problem solving, and for providing support and encouragement.

Barriers to in-service training were not discussed in the literature reviewed here. In a discussion of possible interventions to improve care in nursing homes, Rovner and Rabins (1985) noted the need for in-service training on psychiatric disorders. Such training is usually well-received, but ". . . because of the tremendous nursing care burden that nursing aides carry, perhaps the most effective intervention in the nursing home is to increase the staff-to-patient ratio" (Rovner and Rabins 1985, 120).

7.0 ENVIRONMENTAL DESIGN FOR RESIDENTS WITH DEMENTIA

7.1 Goals of Environmental Design

As individual competence decreases, the environment becomes increasingly important in determining well-being. Environments can be designed to compensate for sensory and cognitive deficits and thereby enhance residents' independence and ability to function to the best of their ability. Environment thereby becomes an integral aspect of the therapeutic program of the facility. The environment can, on the other hand, have a negative effect if it places demands on residents that are beyond their abilities and contributes to problem behaviours or withdrawal.

Environmental design that responds to the needs of residents with dementia also responds to the needs of other elderly residents in many respects. Environmental features relevant to all elderly residents include those intended to support decreased physical abilities or otherwise support good care practices. The needs of residents with dementia are unique in terms of environmental design responding to manifestations of the disease such as catastrophic reactions, wandering or pacing, reality orientation, incontinence, and loss of judgment (MCSS 1989).

Goals for environmental design can be expressed in much the same way as the goals guiding the philosophy of care. For example, Hyde (1989) examined environmental design in eight special care units in Massachusetts in terms of its contribution to the units' goals of enhancing quality of life and increasing residents' sense of mastery within their environment and in their activities of daily living, among other goals. "As one delves more deeply into the care of people with Alzheimer's type of senile dementia or related diagnoses, it becomes increasingly clear that design is not an adjunct but at the heart of a full-service program" (Hiatt 1987; 138).

7.2 Some Principles of Environmental Design

Hiatt (1987) observes that the best environmental design for new construction or an existing facility is one that fits the functional definition of the residents to be served and that is responsive to the services and local geography. Beginning with this premise, there are many good ways of designing for residents with dementia and many good but different models, appropriate for large, specialized units, integrated units, acute care settings and small residential settings.

It is beyond the scope of this paper to review the specific features included in supportive environments described in the literature. Dementia and activities of daily living, available through the Program Technology Branch of the Ministry of Community and Social Services, provides an overview of assistive technologies and environmental design. Living accommodations for seniors. Facility planning and design guidelines. Vol.3 Accommodation for continuing care living available from Health and Welfare Canada, presents facility planning and design guidelines based on residents' needs. Other articles listed in the References section may also be of interest.

Several authors have prepared basic precepts of environmental design for residents with dementia. Several believe creation of a homelike or residential environment is important because the facility may be the residents' home for the rest of their lives (Calkins 1987; MCSS 1989; Ontario Association of Homes for the Aged 1985). An environment as much as possible like the one residents experienced before the onset of the dementing illness creates continuity in their lives and facilitates their adjustment to the new environment. A homelike environment can be fostered by practices in various aspects of the facility and its operations. For example, residents may bring furniture or decorative objects from their own homes. They may have opportunities for dining and socializing in small groups, as they would at home. The area for socializing would be called the "living room", since private homes do not have a "lounge".

Environments can also include prosthetic devices or elements that provide additional functional support to compensate for the residents' diminished capabilities and thereby enable them to function at the maximum level of their ability. This support may be provided as extra information about the environment, such as wayfinding cues, or as a decrease in information, such as camouflaging a door to a utility closet (Calkins 1987; MCSS 1989).

The environment should not provide information that undermines residents' sense of reality. Clocks that do not keep time, orientation boards that do not reflect shifts in the weather or changes in the date, brick-patterned wall-paper that does not feel like bricks, plastic plants that do not feel or smell like growing plants--all can undermine a resident's sense of reality (Ontario Association of Homes for the Aged 1985).

Environments should be calm and quiet; excessive noise can make conversation difficult for the hearing impaired and can be distracting or confusing to other residents (Ontario Association of Homes for the Aged 1985). However, the environment must provide some level of stimulation in the form of enjoyable experiences, sensory pleasures and rewarding activities, because many residents with dementia are unable to initiate and maintain meaningful activities independently.

Stimulation and stress are not the same. A low stimulus environment may be stressful if it does not provide meaningful activities and prosthetic supports (Mace 1987).

The environment should be clearly structured, with each area differentiated from the others and its purpose indicated by furnishings and other cues (Ontario Association of Homes for the Aged 1985). Corridors can be differentiated by colour; bedrooms can be marked by personal possessions and different colour schemes; common areas can be furnished and made distinctive from each other; if possible, a dining area marked by pictures of food, food aromas, a sign depicting a place setting or other symbol, and other such cues can be preserved solely for dining.

Finally, the health and safety of all users of the environment must be maintained (MCSS 1989). Some safety measures respond to the residents' impaired physical abilities resulting from normal aging. For example, glare or abrupt changes in lighting are difficult for the aging eye. Other safety measures are required to compensate for residents' impaired cognitive abilities that may lead to unusual behaviours. A window may be perceived as an exit, even though it is several storeys off the ground (Calkins 1987).

7.3 Benefits of Appropriate Design

Innovation in environmental design has been driven by four forces (Hiatt 1988). The environment is a powerful tool for creating a positive image before elderly persons and their families (an emerging market segment), as well as before peers and regulatory agencies. Also, interest in innovative design is shared by profit-making and non-profit sponsors of facilities and government agencies, thereby creating peer pressure and interest in the area. Families and potential residents are becoming more sophisticated in their tours of facilities and more selective. Finally, prospective staff are sensitive to environments that are stressful or require more energy; a well-designed environment can help attract and retain staff.

The benefits of an appropriately-designed environment include increased efficiencies in operations which in the long term compensate for initial design costs. Environmental cues that reduce excess disabilities, prompt memory and support normalized responses among residents can make resident management easier and more pleasant for staff. Similarly, design and technologies which provide a secure environment can reduce the need for staff surveillance of exits and free this time for activities that are more rewarding for staff and residents. While it is not possible for any social or physical intervention to stop the progress of a dementing illness, the physical environment may be used to slow it down and allow residents to maintain some dignity and self-respect along the way (Calkins 1987; Hiatt 1988).

8.0 THE ROLE OF FAMILIES AND VOLUNTEERS

8.1 The Family Contribution to Care

Residents cannot be treated as isolated identities, but as part of a family unit in which they may have the role of parent, spouse or grandparent (Rapelje 1988). The role of the family and the needs of family members are often recognized in the philosophy of care. For example, the Subcommittee on Institutional Program Guidelines for Health and Welfare Canada noted in its considerations concerning philosophy of care that families have many needs, including information, recognition, professional backup and encouragement (Health and Welfare Canada 1990). Staff of long-term care facilities have a responsibility to meet these needs, particularly during the preadmission and admission process when family members may be experiencing extreme stress. In turn, family members may become valuable participants in care and care planning.

Pynoos and Stacey (1986) found that visiting by family members is considered to have an important impact on the quality of nursing home care because it provides personal services for residents, affects the amount and type of services provided by staff, and has a therapeutic effect on resident well-being. Personal services for residents provided by family visitors were identified in a survey of six special care units in British Columbia through interviews with 39 family members (Gutman and Killam 1989). In terms of activities inside the facility, one-third of family members said they fed their relative at a mealtime or during a snack (or encouraged them to eat) and one-quarter helped care for the resident's clothes. In terms of activities outside the facility, two-thirds of family members said they took care of their relative's financial affairs and more than half (59 percent) reported purchasing, cleaning or repairing goods such as clothing, eyeglasses, hearing aids, or toiletries for their relative.

Pynoos and Stacey (1986) report there is some evidence from the literature that residents with more frequent visitors receive better care than residents who seldom receive visitors. Although the mechanism is unclear, it may be that relatives speak out on behalf of their relative, who may be hesitant or unable to do so. In the survey of British Columbia special care units, 90 percent of the family members said they had as much input as they liked into the care of their relative. When asked how they were involved, the most frequent response was, "If I don't like something, I speak up" (Gutman and Killam 1989).

Finally, visiting by family members may have a therapeutic effect on residents' well-being although again, the mechanism is unclear. It may be that family members bring with them a sense of the world outside the facility and a sense of caring (Pynoos and Stacey 1986).

Pynoos and Stacey (1986) identify two major concerns with respect to visiting: Is it less frequent for residents with dementia? Does a high proportion of residents with dementia discourage visits by relatives and friends to segregated settings? Data from the National Nursing Home Survey provided information about the frequency of visiting for all residents. The survey found that 12 percent of nursing home residents had no visitors in a one-year period but 63 percent had visits on a daily or weekly basis. As residents aged, they were less likely to receive visits from spouses and more likely to receive visits from children.

A study by Hook, Sobal and Oak (1982), cited in Pynoos and Stacey (1986), found that the frequency of visiting decreases with length of residence. Since residents with dementia have been characterized as long-stayers, Pynoos and Stacey (1986) suggest that perhaps residents with dementia receive fewer visitors. However, they note that York and Calsyn (1977) found that the frequency of visiting was unrelated to the extent of the resident's physical or mental impairment, although families had more difficulty coping with mental impairment. Pynoos and Stacey (1986) concluded that the preliminary evidence suggests that residents with dementia do not receive fewer visitors, but the visits may be less enjoyable for family members.

In response to the second question, Meacher (1972, as cited in Pynoos and Stacey 1986) provides some evidence that segregated settings may be discouraging for visitors. Pynoos and Stacey (1986) comment that it seems important that specialized facilities be designed so that families feel comfortable visiting and are encouraged to do so.

Family visits can be encouraged by providing privacy and opportunities for families to gather for festive meals in the dining room or elsewhere, with the food provided by family members or catered by the facility (Rapelje 1988). Staff can also encourage family involvement in care by stressing the importance of family input to the care plan and adapting the plan to meet their concerns whenever possible. The facility's policies and procedures should be fully explained to family members during the pre-admission period and family members should be encouraged to attend regular care planning conferences (Health and Welfare Canada 1990).

8.2 Family Supports

Family involvement may also require specific supports from the facility to maintain and enhance their contribution to the care of their relative. Too often, the nurses' aide is the primary contact and this link may be inadequate. Linsk et al. (1988) recommend that facilities appoint a central family liaison to facilitate family support groups and problem-solving, provides psycho-social services to residents, and mediates staff-family concerns.

The time of admission is particularly stressful for family members, who may be experiencing loss, grief and guilt; long-term care facilities can respond with orientation programs and ongoing family support groups or counselling (Pynoos and Stacey 1986; Rapelje 1988). Family conferences in one program described by Fabisewski and Howell (1986) served three main purposes. They gave families an opportunity to obtain information about Alzheimer's disease and its complications, a venue to express feelings and concerns, and guidance concerning care decisions and use of cardiopulmonary resuscitation at the end stages of the disease.

The survey of special care units in British Columbia (Gutman and Killam 1989) found five of the six facilities offered programs for families. These included family counselling (four units), family support groups (four units), information on dementia (two units), and training in stress management (one unit). Many programs are specially-designed for the families of residents in the special care unit, while other programs are offered generally to families of all residents. However, only the family members associated with one unit were aware to any degree of the programs offered by the unit.

The researchers concluded there is a need to expand programs for families. Once a relative moves into a long-term care facility, the family experiences new needs, including a need for information on how to make the most of visits, and reassurance that their relative is getting the best possible care (Gutman and Killam 1989).

The experience at Maimonides Hospital and Home for the Aged in Montreal has been that strong family ties established between the resident and his or her family before the onset of the dementing illness continue afterwards. Meetings between family members and members of the social service and nursing staffs are held to give family members the opportunity to talk about the home's program and their feelings about having someone they love afflicted with a dementing illness. The home's administrators believe it important that everything be done to maintain strong family ties (Novick 1982).

9.0 SPECIAL CARE UNITS

9.1 Introduction

What is "special" about a special care unit? The literature indicates these units vary considerably and the appellation "special" embraces many characteristics, rather than referring to a single model. Surveys of units labelled "special care units" have found they vary widely in terms of such key parameters as objectives, environmental modifications and staffing. While some studies of residents in individual special care units report improvements in residents' behaviour and social skills, recent surveys of the research on effects on residents agree that there are insufficient research data to provide evidence of either beneficial or detrimental effects of special care units on residents.

Special care units have been defined in theory in terms of key characteristics. Ronch (1987) notes that physically separate units for residents with dementia may not offer special programs for residents with dementia. In turn, special programs may be offered independently from any separate space dedicated to the program or the participating residents. His definition of "special care unit" entails a physical space that serves as a setting for specialized adaptive programs for residents with dementia. Special care units ". . . can provide both environmental (passive assist) and personnel/programmatic (active assist) interventions in a synergetic manner to increase the potential therapeutic outcome for residents and staff" (Ronch 1987, 11).

Separate space and special programs are included in a definition by Gutman and Killam (1989). This definition holds that special care units meet five criteria, in that the unit (Gutman and Killam 1989, 4):

- is physically separated from the facility (nursing home, hospital) of which it is a part;
- has a client population consisting mainly of individuals with dementia;
- has special design features;
- has special activity and/or therapeutic programs; and
- has staff with specialized training.

In practice, separate units for the care of residents with dementia vary considerably in the extent to which they meet these criteria. For example, a survey of long-term care facilities in Minnesota found that of the 22 facilities indicating they had special units for residents with dementia, only one-third provided special training for staff on the unit and only one-third had undertaken special design or structural changes. Yet all the units were defined by the larger facility as a "special care unit".

Facilities may use the label "special care" to indicate some difference in practice or other features of the unit compared with the larger facility (Ohta and Ohta 1988). Practices such as minimal use of restraints or delivery of a particular therapeutic program could be the hallmarks of a unit labelled a "special unit" in one facility, yet could be the expected practice in all units of another facility where such practices were routinely adopted.

The unique circumstance of each facility also contributes to differences in approaches to special care units. Creation of a special care unit may allow a facility to signal "Now we are doing something!", to concentrate scarce resources on a special group of people, to find the freedom to vary from its traditional practices (Hiatt 1987). Many facilities experience a sequential program development, beginning with staff training and special programming. As a next step, residents are clustered on a designated unit and, ultimately, one or more units are established for special care (Weiner and Reingold 1989). And after some experience with it, a facility may phase out its special care unit or adopt an alternative to it. The sponsor asks, "What am I doing on this unit that does not apply to the full population?" (Hiatt 1987).

In developing special care units and special programs, each facility must respond to the perceived needs of its residents, their families and their unique characteristics. Each facility must develop an approach to special care within the context of its standards of practice and philosophy of care, expertise, culture and priorities (Ronch 1987; Weiner and Reingold 1989).

9.2 Perceived Advantages and Disadvantages of Special Care Units

Recent reviews of the literature have found no consistent research data on the benefits or disadvantages of special care units, and discussions of the advantages and disadvantages of these units proceeds without a research data base (Hepburn et al. 1989; Mace 1987; Ohta and Ohta 1988; Ronch 1987). Reviews of the literature for arguments surrounding the issue of segregated care compared with integrated care highlight several central points of debate concerning effects on residents, family members and staff (Gutman 1989; OTA Task Force 1988; Pynoos and Stacey

1986; Rabins 1986).

- **Effects of integration on cognitively intact residents.** Reviewing the literature of effects on cognitively intact residents, Gutman (1989) finds that proponents of integration believe cognitively intact residents benefit from the humanitarian experience of assisting fellow residents with dementia. Proponents of segregation counter that cognitively intact residents are disturbed by the behaviour of fellow residents with dementia and do not appreciate being used as "buddies", especially if such pairings are a staff-saving measure.

- **Effects on staff.** Proponents of integration believe staff could become exhausted and demoralized by caring only for residents with dementia in segregated settings (Pynoos and Stacey 1986). Proponents of segregated care believe special programs allow for development of special expertise that is beneficial to residents and rewarding to staff (Brice 1986, as cited in Gutman 1989). Staff interested in caring for residents with dementia can be recruited (Rabins 1986). Staff in segregated facilities can concentrate on providing one type of care appropriate for residents with dementia, rather than care responding to the different needs of residents with and without dementia. In a locked unit, there is less stress about unauthorized exiting and more time to provide care (Gutman and Killam 1989).

- **Effects on family members.** Reviewing the literature, Gutman (1989) finds families of residents on segregated units may find the units depressing and therefore reduce the frequency of visits with family members there. However, families of cognitively well residents may be upset by contact with residents with dementia in integrated settings. Rabins (1986) finds that families of residents with dementia increasingly advocate for segregated care because they believe it is better, although some families resist placement on a segregated unit because of fear or denial of the diagnosis or because they believe the care is less competent on these units.

- **Effects on residents with dementia.** Diagnosis of dementia is difficult, and segregation of residents with dementia may increase the chances that misdiagnosis will be undetected (Pynoos and Stacey 1986). Lower staff expectations of residents may lead to less aggressive assessment of changes in behaviour and health (Rabins 1986). However, arguments reviewed by Gutman (1989) and others (Mace 1987; Rodenburg 1986) hold that segregated units would allow for design features that facilitate the functioning of residents with dementia and accommodate behaviours such as wandering that would otherwise be managed with chemical or physical restraints. Also, extreme behaviours of residents with dementia would be better accepted in a separate unit. Rabins (1986) notes that more specialized care could be provided by concentrating resources in one unit and by recruiting staff especially interested in this type of care.

- **Effects on quality of care for all residents.** Proponents of integrated care believe all residents need much the same care, given the multiple illnesses of the frail elderly. Rather than creating special units for some residents, the quality of care for all residents should be upgraded. Proponents of segregated care believe the needs of all residents are not the same and that even in a quality care environment, the needs of residents with dementia are different from those of residents without dementia (OTA Task Force 1988).

- **Effects on public policy.** The potential for inadequate and inappropriate care is increased in segregated settings, given the discretion of staff, the inability of residents to speak for themselves, and the possibility of less frequent visiting by family members (Pynoos and Stacey 1986).

Special units for residents with dementia, rather than separate facilities, have been viewed as overcoming some of the perceived disadvantages of segregated care in that they could allow for staff rotation off the unit, interaction between residents with dementia and other residents for various activities, and supervision by resident and family councils. Compared with separate facilities, special units also allow for aging in place and would likely attract less stigma (Pynoos and Stacey 1986).

Special units for residents with dementia could also serve as training sites for aides, nurses, physicians, social workers, activity therapists and administrators; as a source of research data on dementia and care techniques; and as an information resource for the community (Rabins 1986).

9.3 Benefits of Special Care Units for Residents With Dementia

In her work for the Office of Technology Assessment, U.S. Congress (OTA 1986) and in other work (Mace 1987), Nancy Mace reported that some special care programs report initial improvements in participants and less precipitous decline thereafter. Improvements are usually indicated in terms of decreases in extreme behaviour, such as wandering and agitation, and increases in socially appropriate behaviour, such as humour and a relaxed appearance. Programs fail to find consistent improvements in language skills, motor skills or memory, areas that likely are impaired by the dementia.

The benefits of special care programs may result from three contributing factors. In experimental situations, the enthusiasm and attention of the staff usually lead to improvement among residents. Also, residents who are severely impaired may be responsive to even small improvements in their physical or psychosocial environment and thus responded favourably to the wide range of environmental modifications introduced in various programs. Finally, many of the benefits may have resulted from removal of excess disabilities through maintenance of good physical health and appropriate forms of care.

While initial reports are promising and underscore the principles of quality care in any setting, Mace (1987) believes not enough is known about special care to assess its benefits accurately. Benefits have been reported in small programs undertaken by dedicated staff, and it is not known how well these interventions can be practised on a larger scale within the long-term care system. Also, behaviour gains are maintained only while special care is continued, and programs which have a policy of discharging residents after rehabilitation may establish a "revolving door" pattern of discharge, worsening of symptoms and subsequent readmission.

The diversity of special care units has made it difficult to answer the question, "Do special care units work?" Key issue areas have been proposed by Ohta and Ohta (1988) to guide future research and to provide a conceptual framework. First, what is the relationship between unit characteristics and patient benefits? Does a total environment need to be created, or will partial measures yield partial benefits? Is there a lower limit of adaptations that must be implemented before any residents will benefit, and an upper limit of adaptations beyond which few residents will benefit?

Secondly, are there different types of special care units that are ideally suited to residents at different stages of a dementing illness? Are residents with mild or moderate forms of dementia best suited to one type of special care unit while residents with moderate to severe forms are best suited to another? Finally, methodological issues must be overcome through well-founded research strategies.

Despite the diversity of special care units, researchers surveying special care programs in the United States (Weiner and Reingold 1989) discerned a common organizational framework for developing programs and special units for residents with dementia. This framework includes setting objectives, development of admission and discharge criteria, environmental modifications, special activities, staff training and support, and family group programs. Special care units will be discussed in subsequent sections in terms of these components, plus care strategies and programs.

9.4 Goals and Objectives of Special Care Units

The literature discusses goals identified by researchers on the basis of concepts of good practice and goals identified through surveys of operating units. Mace observes that the most successful day programs and residential programs for persons with dementia resemble each other in key factors and strive towards the following common goals (OTA Task Force 1986, 259):

- to prevent excess disability due to other health problems or medication;
- to use as few psychotropic drugs as possible, and use few if any, physical restraints;
- to maximize an individual's ability to hear and see;
- to restore remaining function rather than to restore function lost through the disease process;
- to reduce long hours of idleness;
- to use activities and a caregiving style that enhance resident comprehension of appropriate roles as friend, family member, or volunteer, and that reinforce a sense of personhood and dignity;
- to create a "homey" environment in which residents are well-dressed and well-groomed;
- to use a mix of flexibility, creativity and both structured and non-structured approaches to activities;
- to emphasize the importance of respect for residents and to individualize approaches;
- to recognize the importance of environmental accommodation and the significance of a benign, nonstressful, supportive environment;
- to support the family in a continuing relationship with the resident.

These goals overlap with those identified in a survey of 35 special care programs (including 22 special care units) in the United States, although the former seem to provide stronger direction to care practices. The survey found the following objectives, listed in the order of the frequency cited (Weiner and Reingold 1989, 15):

- to provide a safe, secure, and supportive environment from nursing and socialization perspectives;
- to improve the environment and community of mentally intact patients;
- to reduce feelings of anxiety and confusion through environmental and communications support;
- to help patients reach or maintain their optimal levels of physical and cognitive functioning;
- to provide holistic patient care;
- to offer care providers understanding, training, education, and freedom from excessive stress;
- to recognize that demented patients are entitled to experiences and activities that will enhance the quality of their lives;
- to recognize that patients are autonomous and can expect that their special needs and those of their families will be met with sensitivity and appropriateness;
- to provide patients with opportunities to succeed, which will build their sense of self-esteem, dignity, and hope.

Some facilities responding to the survey also set clinical goals, such as elimination of restraints, elimination of catheters and diapers for incontinent residents, and minimum use of psychotropic drugs.

Considerable diversity among goals was found in a survey of seven nursing homes with special Alzheimer's units and one with a day program for persons with Alzheimer's disease (Hyde 1989). Several had adopted a medical model, in which residents were referred to as patients and emphasis was placed on hygiene, management of the disease process and maintenance of physical health. Other units emphasized continuity with the residents' families and life experience, and viewed the unit as an extension of the community in which the resident lived prior to admission. Some units set as a goal the maintenance of as high a level of functioning as possible, with improvement expected in some cases, while others emphasized the need to accept the progressive nature of the illness.

9.5 Size of Unit and Type of Room

Ohta and Ohta (1988) found the size of special care units to be determined through practical considerations related to available space and budgets, rather than theoretical considerations of optimal arrangements. However, they noted that the number of residents on a unit has implications for residents' relationships and activities on the unit. A unit with 10 residents allows them to see a small group of fellow residents each day, thereby promoting socialization and a sense of intimacy. On a larger unit with 49 residents, the social stimuli are too diverse to allow residents to develop intimacy.

Johnson (1989) recommends no more than 15 beds in a special care unit, to avoid over-stimulation by the sheer number of residents and their noise and activities, plus the number of staff and their activities.

The survey of 22 special care units in Minnesota (Hepburn et al. 1989) found the mean number of residents in each unit was 34, and most were in double rooms. The survey also found that nursing homes with more than 100 beds were more likely than smaller homes to have a special care unit, with 18 percent of the larger homes having a special care unit compared with 2 percent of the smaller homes.

Three major nursing home chains in the United States report an average unit size of 24 to 31 beds. Hillhaven Corporation operates 32 Alzheimer's units with a total of 1000 beds and an average of 31 beds in each unit. ARA Living Centres reports an average of 24 beds in each of its 21 Alzheimer's units, and Manor Care operates six units with a total of 167 beds, or an average of about 29 beds in each unit (Wagner 1987).

A survey of six special care units in British Columbia found the number of residents in each unit ranged between 20 and 30 in special care units in intermediate care facilities and between 25 and

38 in units in extended care facilities. Staff indicated an ideal maximum number of residents for special care units. The number selected by staff in intermediate care facilities ranged between six and 30, with a mean of 18. The number selected by staff in extended care ranged between 12 and 38, with a mean of 26.

Staff also differed in their perceptions of ideal number of residents in each room. Of the staff in intermediate care facilities, 69.2 percent believed there should be no more than one resident in each room and the remaining staff believed there should be no more than two residents in each room. Of the staff in extended care facilities, 15.8 percent believed there should be no more than one resident in each room, 57.9 percent believed there should be two residents in a room and 26.4 percent believed there should be three or four residents in a room (Gutman and Killam 1989).

Most of the 19 units considered by Ohta and Ohta (1988) had rooms for two or three residents, an arrangement usually adopted because of available space and budget constraints without reference to beliefs about ideal arrangements In one case, however, the unit used private rooms because staff believed residents had a need for privacy and social stimulation occurred in communal spaces and activities. The staff of another unit using shared rooms believed equally strongly in the benefits of their approach, saying private rooms increased isolation and withdrawal and hastened functional decline, while a roommate provided a vital source of social stimulation. In a similar vein, Johnson (1989) viewed room sharing as a means of social bonding, with careful selection of roommates and monitoring of their compatibility.

9.6 Admission and Discharge Criteria

Admission and discharge criteria are used to select persons for special care from the large numbers of persons in long-term care who have dementia. No generally accepted criteria have been developed for admission to special care units, although many use the following (OTA Task Force 1986):

- presence of irreversible dementia, excluding persons with mental retardation or with treatable dementia;

- presence of disruptive behaviours, such as incontinence, wandering and agitation, that are often used to exclude persons from other programs; and

- ability to benefit from the program, usually ascribed to persons in the mid-stage of their illness who exhibit problem behaviours and who can respond to social stimulation.

Other commonly-cited criteria address age limits, usually age 60 or 65; priority to the facility's residents over applicants from outside the facility; and ability to ambulate (Hepburn et al. 1989; Weiner and Reingold 1989). In addition to these commonly-cited criteria, a survey of special care units in British Columbia found that the six units set criteria related to assessment by the B.C. Long Term Care Program at a prescribed level of care (variously Intermediate III or extended care).

A survey of 22 nursing homes in Minnesota with special care units found that behaviour was a primary determinant of admissions, since little diagnostic precision was required and most accepted the admitting diagnosis of the resident's physician, usually a non-specific diagnosis (Hepburn et al. 1989).

Admission and discharge criteria largely determine the profile of residents on the unit, with implications in turn for staffing and program needs. Two models are discussed by Ohta and Ohta (1988). In one, residents are admitted with a view to permanent placement and remain on the unit as their dementia progresses and care needs increase. A diagnosis of dementia is the primary admission criterion and a highly heterogeneous population with varying needs and abilities is admitted. Residents are not discharged, but continue on the unit. "In these units, as a result of the progressive patient decline, the nature and character of the unit itself undergoes transition" (Ohta and Ohta 1988, 806).

In the other model, admission and discharge criteria are used to select and maintain a homogeneous population, one that is believed to benefit from the program. Admission criteria reflect physical, cognitive and behavioural characteristics suited to the unit's care program and goals, and residents are discharged when for physical, cognitive or behavioural reasons, they no longer benefit from the unit's program.

Both models were observed in the Weiner and Reingold (1989) survey of 35 programs for persons with dementia (including 22 special care units). The special care units were used for short-term placement in 10 facilities, for progressive, intra-unit placement in three facilities, and for long-term, permanent placement in four facilities. (No further details of subsequent placement arrangements were provided.)

The survey of 22 special care units in Minnesota found that all but one facility viewed placement as permanent and most discharges (81.8 percent) occurred because of death. The authors observed a lack of articulated discharge criteria, which they suggested may be due to the newness of the units; the median length of operation was two years (Hepburn et al. 1989).

The survey of six special care facilities in British Columbia found that three would discharge residents to a regular unit if their behaviour improved and they no longer needed the care of the unit, and three would discharge if the resident's condition deteriorated to the point he or she was no longer able to wander and/or required a heavier level of care (Gutman and Killam 1989). Residents were also discharged from three units if their behaviour became unmanageable; these units set admission criteria that screened out residents who are physically aggressive.

Of the 60 discharges from the six special care units in the 12 months previous to the survey, 28 had died, 15 were no longer ambulatory or at risk of wandering, and another 11 were discharged because they could no longer be managed on the unit. Twenty-two residents were discharged to a regular extended care facility and the others were discharged to a psychogeriatric facility (4), a regular intermediate care facility (3), or care in the family home (2).

Some facilities have established step-down units to care for residents discharged from the special care unit. In these units, the residents are provided with special sensory stimulation, passive exercise and nutrition support, and are kept as alert and physically active as possible (OTA Task Force 1986).

9.7 Characteristics of Residents on Special Care Units

The survey of special care units in British Columbia obtained information about residents' level of care requirement, age, sex, ability to ambulate and diagnosis. Most of the residents in intermediate and extended care facilities were classified at the same care level, Intermediate III. Compared with residents of intermediate care facilities, residents of extended care facilities included a lower proportion of women, persons over the age of 80, and ambulatory residents, and a greater variety of diagnoses.

Most of the residents in intermediate care facilities were classified by the B.C. Long Term Care Program at the Intermediate III level and some were at the Extended Care level. Most residents of units in extended care hospitals were also classified at the Intermediate III level, which may reflect the fact that there are no special care unit beds in Intermediate care facilities in the areas where the hospitals are located.

In the three units in intermediate care facilities, 65 to 80 percent of residents were aged 80 or older, while in the three units in extended care hospitals, 40 to 64 percent were aged 80 or older. The extended care facilities also had a more equal sex distribution than the intermediate care facilities, with 49 to 60 percent of residents female, compared with 55 to 85 percent females in the intermediate care facilities. Most of the residents of intermediate care facilities (85 to 100 percent) were ambulatory. In one extended care facility, only 8 percent of residents were ambulatory and in the other two units, 66 percent and 75 percent of residents were ambulatory. While the residents of intermediate care facilities were described generally as having dementia, residents of the extended care facilities included persons with psychiatric disorders, head injuries, Huntington's disease and alcohol-related dementia.

Residents of all facilities were generally characterized by staff as being a danger to themselves. Staff at five units also viewed the residents as being disturbing to others. Staff were asked to indicate the behaviours exhibited by most, some or few residents, choosing from a list of 21 behaviours. Fifty percent or more of staff believed most residents had difficulty wayfinding, trespassing and resistance to care. Between 25 and 49 percent of staff believed most residents had inappropriate eating behaviours, repeated chattering and physical aggression to staff.

When asked which behaviours were very difficult to manage, 25 percent or more of staff identified the following: spitting, resistance to care, physical aggression towards other residents, physical aggression towards staff, and repeated banging.

Half of the staff indicated that few residents tried to leave the unit unauthorized. All the units (except the one in which most residents were non-ambulatory) were locked. None of the units used personal restraints to prevent exiting but most did use restraints, usually lap restraints in chairs, to prevent falls. Staff were concerned about the risk of injury using restraints and used them only at a physician's request.

9.8 Care Strategies and Therapeutic Approach

The focus of resident care on a unit depends on underlying beliefs about residents' limitations and potentials. Drawing on observations and reviews of 19 special care units, Ohta and Ohta (1988) identified three different approaches to resident care, each with unique therapeutic features. In one type of unit, the focus of resident care is custodial care, with residents encouraged to perform a few activities of daily living. Characterized by the authors as a "no frills approach", this model concentrated on keeping the resident alive and managing behaviour as expeditiously as possible, with routine use of restraints and psychotropic drugs.

In another type of unit, maintenance of ability to perform activities of daily living skills is emphasized along with strategies for minimizing memory and behaviour problems. In this type of unit, individual care plans are prepared and include activities to exercise each resident's physical, cognitive and social skills. Plans are monitored and modified as needed. Restraints and psychotropic drugs are used as little as possible, as a last resort after other methods of controlling behaviour have failed.

A third type of unit accepts the focus of the second type as a base and pursues quality of life dimensions such as dignity, self-esteem, privacy, and respect. The underlying premise of this model is that residents retain some capability to think and make decisions, to feel, and to socialize, and should be treated accordingly.

9.9 Programs and Special Activities

The survey of six special care units in British Columbia (Gutman and Killam 1989) asked staff to describe the goals of programs offered on the units. The most frequent responses were to:

- keep residents busy (7);
- maintain/optimize function (7);
- provide fun, enjoyment/enhance quality of life (6);
- maintain/optimize physical status/mobility (5);

- decrease stimulation/avoid over-stimulation/calm (5);
- socialization (interaction with others) (4);
- stimulate/activate residents (4);
- set individual program goals (4);
- orient residents (3).

The approach to activities in 21 facilities surveyed by Weiner and Reingold (1989) varied from a highly structured routine in five facilities, to a more flexible adaptation of institutional programs and weekly variety in the others. Nineteen facilities indicated the activities used most frequently on the special care unit, with physical exercise (16 facilities) and music (ll facilities) topping the list, followed by reality orientation, sensory stimulation and cognitive stimulation, each reported by six to eight facilities (Exhibit 9.1).

Weiner and Reingold (1989) note that these activities are comparable to those ranked as most successful with persons with dementia participating in adult day programs in a survey of 444 such programs in the United States (Mace 1984a,1984b). Activities regarded as the most successful with participants with dementia were (in rank order): singalongs, physical exercise, walks, reminiscence groups, visits from children, active games, outings, listening to music, reality orientation and visits from pets.

Music therapy and outdoor walks were also rated as effective with residents with dementia by staff interviewed in the British Columbia survey (Gutman and Killam 1989). Staff were asked to indicate whether they had had experience with selected therapeutic programs and whether they believed these programs were effective with residents of special care units most times, sometimes or never. Music programs, outdoor walks, exercise programs, pet visitor programs and validation therapy were rated as being effective most of the time by 50 percent or more of the respondents who had had experience with the programs (Exhibit 9.2).

Exhibit 9.1

Activities Reported by 19 Special Care Units Surveyed in the United States

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- Physical exercise, such as walks, adaptive sports, wheelchair exercise (16 facilities)
- Music, such as singing, active/passive listening (11 facilities)
- Reality orientation, remotivation (8 facilities)
- Sensory stimulation and awareness conducted by occupational therapy department (8 facilities)
- Cognitive stimulation such as word games, reminiscence (6 facilities)
- Crafts (5 facilities)
- Bingo (4 facilities)
- Grooming, basic skills classes (3 facilities)
- Cooking (2 facilities)
- Horticulture (2 facilities)
- Pet therapy (2 facilities)
- Ice cream and cocktail parties (2 facilities)
- Sheltered workshop (1 facility)

Audrey S. Weiner and Jacob Reingold. 1989. Special care units for dementia: Current practice models. The Journal of Long-Term Care Administration:Spring 14-19. 18.

Exhibit 9.2

Experience with Selected Therapeutic Programs and Perceived Effectiveness of Programs

			Effective		
	Base	Have Had Experience	Most Times	Some Times	Never
Music therapy	37	97.3%	91.3%	8.3%	0.0%
Outdoor walks	35	82.9	85.7	10.7	3.6
Pet visitors	35	97.1	61.8	38.2	0.0
Exercise	36	97.2	57.1	42.9	0.0
Validation therapy	34	50.0	52.9	47.1	0.0
Reality orientation	34	67.6	5.6	77.8	16.7
Plant therapy	35	68.6	21.7	78.3	0.0
Crafts	34	91.2	6.7	76.7	16.7

Gutman and Killam. 1989. Special care units for dementia: Staff and family perceptions. The Gerontology Research Centre, Simon Fraser University. 47.

The Fishkill Health Related Center described by Ronch (1987) mainstreams residents with dementia with residents without dementia for various activities, according to the residents' individual needs. Such an approach requires periodic reassessments of functional capabilities and the appropriateness of the various activities to provide satisfaction and success. This approach is viewed as promoting the highest level of competency while decreasing the distance between "them" and the "normal" rest of us, a distance that fosters a role for demented residents based on their behaving stereotypically. In this vein, activities for residents with dementia are not "therapy" in name or philosophy, since this approach implies a disease and the need for a cure. Rather, activities are undertaken because they reaffirm the self or reawaken old interests.

9.10 Staffing and Staff Training

The ratio of direct care staff to residents reported in three surveys of special care units ranged from a high of between 1:3 and 1:4, to a low of between 1:7 and 1:12 for the day shift (Gutman and Killam 1989; Ohta and Ohta 1988; Weiner and Reingold 1989). Ratios usually decreased in the evening shift, and again in the night shift. Night shift ratios reported in a survey of six British Columbia special care units ranged generally between 1:12.7 and 1:40, although one unit reported 1:83.3 (Gutman and Killam 1989). A survey of 21 special care units across the United States reported night ratios of 1:6 to 1:27 (Weiner and Reingold 1989).

Weiner and Reingold (1989) report that staff ratios varied with resident care needs. Units that had discharge criteria related to a resident's need for increased levels of care also reported fewer staff and a lower ratio. In the survey of six units in British Columbia, units operated as intermediate care facilities had lower ratios than units operated as extended care facilities and serving a resident group with greater care requirements. The three units operated as extended care facilities had daytime ratios of 1:3.5, 1:4.5 and 1:7.1, compared with daytime ratios in the intermediate care facilities of 1:6.6, 1:8.5 and 1:8.9 (Gutman and Killam 1989).

Staff on the units in extended care facilities were more likely than staff in the intermediate care facilities to believe the number of staff and type of staff on the unit are sufficient for adequate care, although the differences were not statistically significant (Gutman and Killam 1989). Of the 40 staff interviewed, 39 intended to continue working on the special care unit because they found the work challenging, rewarding and/or interesting (22) and because they liked the residents (18), among other reasons.

Ohta and Ohta (1988) believe that units with a high ratio generally experience less stress among staff and maintain a consistent staffing pattern, in which the same staff work on the unit without rotating off. Staff support groups are used to handling any stress that does arise among unit staff. Units with a low ratio experience more stress among staff and tend to rotate the staff off the unit. "Staff stress, in these units, appears to be the dominating force directing staffing consistency and necessitates the rotation of the staff" (Ohta and Ohta 1988, 805).

The survey of 22 special care units in the United States (Weiner and Reingold 1989) found that several units modified traditional assignments of tasks. In three facilities, nurses' aides conduct reality orientation, remotivation, grooming and activity programs. Five facilities employ registered nurses or social workers as full-time or part-time clinical coordinators on the special care unit, responsible for new program development, staff education, problem solving and program marketing (within privately-operated facilities).

The survey also found innovative approaches to staffing. Recreation programs were operated between 10 a.m. and 6 p.m., and staff were assigned a shift between those hours. Part-time feeders, assistants or nurses' aides were employed on the evening shift to help with dinner and bedtime; lounge aides help nurses' aides supervise lounge areas. The special care units surveyed in British Columbia (Gutman and Killam 1989) also indicated increasing staffing in the late afternoon and evening, when staff believed noisiness and other problem behaviours among residents increased. Units either added another care aide for half a shift or scheduled an activity worker to be on the unit in the late afternoon or evening.

Provision of training on the care of residents with dementia varies considerably among special care units, with some providing little or no training and others providing orientation before work on the unit and ongoing in-service training. The survey of special care units in the United States (Weiner and Reingold 1989) found that 14 of 21 units provided training prior to development of the unit or special training for new staff or both, and 10 provided continued in-service training. The survey of 22 special care units in Minnesota indicated that only eight provided special training to staff on the special care unit beyond general orientation to the facility, and only five reported special in-service training for staff on the unit. Most of the staff of special care units surveyed in British Columbia indicated they had received special education on working with special care unit residents, with 33 of the 40 staff interviewed (82.5 percent) indicating they had received training.

9.11 Environmental Design

Surveys of special care units have found, again, a range of approaches to environmental modifications. Ohta and Ohta (1988) found one unit that was virtually indistinguishable from any traditional long-term care nursing unit, except for an alarm system. At the other extreme, another unit had rooms furnished with the resident's furniture, carpeting throughout, and photograph boards and pictures relevant to the residents' backgrounds.

The survey of special care units in the United States (Weiner and Reingold 1989) found that about half were developed through conversion of existing facilities. Of 26 special care units or facilities offering special programs, 22 had increased security and visual access, most frequently by alarming, coding or securing of exits (17). Eleven had introduced measures to increase orientation through reality orientation boards, large calendars and daily schedules (6) and through colour-coded furniture and corridors (6). Nine had modified the communal space through increased square footage (7) or addition of a garden or walkway (4). Seven had tried to control noise through use of carpeted tiles (5) and elimination of the intercom or public address system (2).

The survey of 22 special care units in nursing homes in Minnesota (Hepburn et al. 1989) found that none were new units, specially designed for residents with dementia, and only eight had been remodelled or changed in any way to accommodate these residents. Sixteen had special alarm systems and nine were locked.

In the survey of six special care units in British Columbia, all units except the one caring for non-ambulatory residents were locked to prevent unauthorized exiting. All had access to a secured outdoor area. Strategies used to reduce sensory overload and calm residents were background music (4), use of pastel colours (3) use of small rooms for individual activities or to isolate noisy residents (2) and reduced lighting (1). Gutman and Killam (1989) found that minimal use was made of aids to facilitate wayfinding and orientation. Aids that were used included clocks and calenders (5), extra large signs (3), reality orientation boards (3) and pictures of significance to residents on their doors (1).

About half the staff believed the layout, interior design and furnishings of the unit met residents' needs. Improvements suggested by staff included quiet rooms for withdrawal and privacy, changes to lounge arrangements, such as larger lounges or more lounges, and a large, secure outdoor area (Exhibit 9.3). Suggested improvements included a central nursing station with a view of the whole unit, a staff lounge or dining room on the unit, an enclosed nursing station secure from residents,

Exhibit 9.3

Staff Suggestions for Improvements on Six Special Care Units in British Columbia

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Improvements to Layout

- Quiet rooms to withdraw to, rooms for privacy, rooms to calm agitated or disruptive residents; nicely decorated (19)
- Bigger lounge, more lounges, separate lounge and dining room (11)
- Specifically designed activity rooms and/or activity kitchen on unit (9)
- Large outside area totally secure, accessible from unit, entirely visible from unit (8)
- Continuous walking area without dead ends (7)
- Improved ventilation, preferably with windows that open (7)
- More windows, to improve views out, increase lighting, improve ventilation (6)
- Wider hallways (5)
- More room for wandering (5)
- Nursing station located so whole unit can be seen (5)
- Wheelchair-accessible toilets with grab bars (4)
- Dining room on unit (3)
- Solarium, to create sense of being outside (3)
- More one-bed and two-bed rooms (3)

Interior Design

- More homelike appearance (i.e., using aquarium and pictures) (7)
- Provide things such as wall hangings to touch (6)
- Provide more light, preferably natural light (4)
- Camouflage exit doors (2)
- Non-glare flooring (2)
- Uniform floor colour (2)

Furniture

- Build in or bolt down furniture, since residents move and pile it (6)
- Provide more rocking chairs (4)
- Avoid cloth furniture (4)
- Strong furniture with arms, furniture that gives good support (3)

Gutman and Killam. 1989. Special care units for dementia: Staff and family perceptions. The Gerontology Research Centre, Simon Fraser University. 34.

larger bathrooms, a larger medication room or locked room secure from residents, and cameras to monitor exit doors.

About two-thirds of family members interviewed believed the unit layout, interior design and furnishings met their needs and those of the residents. Suggestions for improvements included softer chairs, larger lounge, more space for walking, better ventilation, more large windows, a dining room on the unit, toilets close to common areas and more colour and visual stimulation.

9.12 Costs of Special Care Units

Costs of special care were not discussed frequently in the literature reviewed here. Mace (1987) notes there is concern that the ideal model of care for residents with dementia would be prohibitively expensive. Although good care for residents with dementia will not be cheap, cost issues cannot be resolved until more is known about the kinds of care residents with dementia require.

A spokesperson for ARA Living Centres, a nursing home chain in the United States, was reported as saying that the initial cost of renovating and equipping a unit in its 24-bed Alzheimer's units is $60,000 to $70,000. The chain finds that daily resident care costs are $8 to $10 more for each resident with dementia, compared with standard program costs. Costs are higher because residents with dementia require 30 to 60 minutes more staff time daily than other residents. The key cost components of specialized care are architectural modifications, staff education and specialized therapy (Wagner 1987).

Grossman et al. (1986) describe creation of a special care unit at The Hebrew Home for the Aged at Riverdale, a 951-bed facility in the Bronx, New York. While the process of creating a 44-bed unit within the facility required considerable consultation with staff, families and residents, many of the environmental modifications (i.e., colour coding doors and hallways, erecting mirrors to improve staff view points, mementos marking residents' doors) were achieved at nominal cost.

Staff and staff training costs increased, however. The number of staff on the unit was not indicated, although the authors noted that few facilities have the resources to provide staffing levels approaching a 1:1 ratio, as is the case in some demonstration projects. Since the care needs of residents on the unit were greater than the care needs of residents on other units, there was some reallocation of staff among all units to reflect care requirements. After the unit was established, staff morale decreased despite staff meetings and previous consultation. Daily 15-minute meetings of day and evening staff and nursing and psychiatric social work supervisors were therefore instituted to allow staff to air problems, discuss possible strategies and receive additional training. All staff also attend bimonthly community grand rounds.

Nurses' aides were assigned to on-the-unit activities such as therapy, exercise and arts and crafts. "This approach increased their understanding of the reasons for the activities, provided education in patient-support techniques, extended the effectiveness of the program beyond their limited activity slot through ongoing integration and teaching and developed a means of support to non-nursing personnel" (Grossman et al. 1986, 83).

9.13 Alternatives to Special Care Units

Regardless of whether a facility houses a special or separate unit for residents with dementia, it likely has some residents with dementia requiring specialized care. As the Subcommittee on Institutional Guidelines for Health and Welfare Canada observed (Health and Welfare Canada 1990, 52):

> In practice, the demography of long-term care does not permit "segregation" in any rigorous sense: cognitive impairment and behavioural disturbance are matters of degree, and residents who are affected to some extent by such problems are likely to be the majority in most facilities. Only a fraction of the residents in this group could be accommodated in separate, specialized units or programs. The needs of the less seriously impaired must be addressed by adapting the regular programs and physical environment of the facility.

Ideally, every facility would offer an architecturally supportive environment and programming suited to the needs of these residents and their families. In reality, many facilities are not designed for residents with dementia and have insufficient funds to renovate or increase staffing levels. (Sandel, Fisher and Hollander 1989). In practice, such facilities are counselled to make the best use of available resources, proceed slowly, and accept small improvements as being better than none (Ontario Association of Homes for the Aged 1985).

Sandel, Fisher, and Hollander (1989) describe efforts to improve the quality of life for residents and staff on a 47-bed second floor unit of a skilled nursing facility in Connecticut. The unit was described as chaotic, noisy, and the least desirable location to live and work. A therapeutic recreation director and administrative intern observed residents' behaviour, staff activities, and the use of time and space on the unit for 10 days. Their observations included marked increases in agitation before and after the evening meal and rushed lunch periods; the pooling of immobile residents in the solarium without staff attendance; and programs conducted for up to 30 residents at a time.

The most significant intervention was a restructuring of staff management on the unit, with emphasis on a team approach by the director of nursing and the recreation director. Efforts were made to share the workload, with nursing assistants participating in recreation activities when possible and the recreation director assisting at mealtimes, for example.

Efforts were also made to restructure the flow of time and space to facilitate smoother transitions between events, since unstructured periods before meals and other scheduled activities led to agitation. Staff also recognized that a highly structured program was best for residents with dementia. Interventions in this regard included a morning ritual of meeting, greeting and active exercise, followed by regrouping for quiet activities before lunch. Small group and large group activities were scheduled on and off the unit in the afternoon, again followed by quiet activities before dinner.

Staff, families and visitors all observed a decrease in agitation and noise. The active morning period fostered communal awareness and led to better appetites. The decrease in agitation allowed individual residents to tolerate participation in activities outside the unit and families became more willing to accompany them to these events. Increased staff morale was evinced by increases in teamwork and expressions of pride. The authors concluded, "Although the reality is that most long-term care facilities are not architecturally designed for patients with dementia, learning to creatively manage a less than ideal program can have positive results: a calmer unit with less agitated and more awake patients" (Sandel, Fisher, and Hollander 1989; 23).

Another alternative to special care units is creation of in-house day care programs, in which residents from different units come together for special programs or services designed for their unique needs (Hiatt 1987).

Schiffe and Rapelje (1985) describe activities to improve the environment for mentally frail elderly in two nursing homes built in Niagara Falls in the mid-1950s. Goals for the activities included providing features that orient residents and sustain remaining skills; creating individualized bedrooms; and facilitating participation of staff and residents from other units in the project. These residents were asked to help choose wallpaper for the rooms of residents with dementia, since the latter could not participate.

Activities included painting corridors, handrails and the doors to residents' rooms different colours, as aids to wayfinding. Pictures were selected and placed to serve as a focus for conversation and reminiscence, as a contribution to the aesthetic environment, and as an aid to wayfinding. Orientation boards and clocks were placed in the dining room and bulletin boards with residents' names and photographs were placed outside the residents' bedrooms on a trial basis. Inside the bedrooms, bulletin boards were hung for photographs, cards and other mementos, privacy curtains were installed, and individual wall lamps were installed on a trial basis. Non-toxic plants were hung in lounges and dining areas.

While the sponsors wished they had a larger budget for the project, they have observed changes. Staff said they found the environments more attractive and appreciated the effort. Staff may also have become more aware of how the physical environment can help residents function and may take an ongoing interest in changing it.

10.0 LEGAL AND ETHICAL ISSUES

10.1 The Need for Consent

Legal and ethical issues arise most frequently when residents with dementia must make decisions concerning finances or personal care and medical treatment. Physicians must obtain a valid consent for all medical procedures and the facility must obtain consent for any other interventions that involve possible risk or interference with the individual's autonomy or physical integrity. Actions taken without consent (or in opposition to a valid refusal) can lead to litigation (Health and Welfare 1990).

In general, common law strongly supports a mentally competent individual's right to accept or reject treatment; in the case of persons who are not mentally competent, common law and health care practice have developed several measures. Most commonly, a substitute decision-maker is selected and this person is expected to make the decision the way the individual would have, drawing on any available information concerning the individual's wishes. If the individual's wishes are unclear, the decision is made the way a reasonable person would decide in his or her own best interest (Health and Welfare 1990).

Under Canadian law, adults are assumed to be fully capable of making informed decisions and understanding their consequences unless there is compelling evidence to the contrary. Such evidence would usually lead to a medical examination to assess the degree and nature of the individual's competence for decision-making. An initial assessment of the competence of residents of long-term care facilities should be made at the time of admission and reviewed regularly, particularly at the time when consent for a major intervention is required. Some residents with dementia may be able to provide consent for routine care but may be deemed incompetent to handle their estate, while others may be found to have a fluctuating degree of competence based on such factors as the course of the medical disorder or reaction to medication.

Residents in the very advanced stages of dementia may be assessed as not competent to make any decisions concerning health or finances, and requiring an arrangement for substitute decision-making.

Legislation concerning substitute decision-making, through guardianship or trusteeship, is a provincial responsibility and varies from province to province. Legislation governing the appointment of a guardian of the person gives a guardian responsibility to ensure that adequate care and protection are provided to a person shown to be in need of such services and unable to provide them for himself or herself. Legislation governing the appointment of a trustee of the estate allows for the appointment of a trustee (either a public agency or a private individual) to take responsibility for a mentally incompetent individual's financial affairs.

Some provinces also allow an enduring power of attorney. Power of attorney allows an agent to act on behalf of the donor without diminishing the powers of the donor. Since the donor is assumed to be responsible for monitoring the activities of the agent, power of attorney terminates when the donor becomes mentally incompetent and can no longer do so, unless an enduring power of attorney has been granted. Some provinces have also established agencies and procedures for protecting the interests of adults with long-term mental disabilities or other problems (Health and Welfare Canada 1990).

Arrangements for substitute decision-making concerning financial affairs can be made through the appointment of a trustee of the estate or through the use of an enduring power of attorney where permissable. Arrangements for substitute decision-making concerning medical treatment is more problematic, particularly in provinces without effective legislation concerning guardianship of the person. Health and Welfare Canada (1990) recommends that long-term care facilities need to address this issue by clearly defining their policies concerning informed consent and by obtaining legal advice about their implementation. While many personal care activities and non-intrusive medical procedures can be pursued with the consent (informed or otherwise) of the resident and the informed input of family members, a valid consent must be obtained for intrusive treatments such as surgery, intravenous feeding or psychotropic medication.

The basic requirements of a legally valid consent are that it be given voluntarily, that it be given following a full disclosure of all relevant information, that it be directed towards a specific act or series of acts, and that the resident providing the consent be mentally competent and capable of appreciating the implications of the decision. If the resident is not competent to give or withhold consent, the physician may consider the following options, in descending order:

- seeking consent from a guardian of the person already appointed by the courts;
- seeking consent from a relative recognized by the facility and by the law as the resident's next of kin, who is known to be competent to make the decision, and who understands and accepts this responsibility;

- obtaining and documenting the decision of two physicians that the resident is not competent to consent and that the proposed procedure is necessary for the resident's well-being;

- making an application to the court for the appointment of a guardian or substitute decision-maker under the available legislation, if time permits (Health and Welfare Canada 1990).

10.2 Acute Medical Decision-Making

Kayser-Jones and Kapp (1989) describe the substitute decision-maker for medical treatment as an advocate for the resident. They question the assumption that the individual or body empowered to make decisions on behalf of a resident (presumably because of their relationship with the resident and knowledge of the resident's likely wishes) is also the best candidate to serve as advocate for the resident in acute medical treatment decision-making. While the advocate must be loyal solely to the resident's wishes, the substitute decision-maker must balance the resident's wishes against other competing interests, including economic and legal considerations and emotional involvements.

Ideally, the medical decision-maker should have the following characteristics:

- no conflict of interest with the resident, or the ability to overcome any conflict;

- the ability to participate in and contribute to the decision-making process in an informed and conscientious manner, with adequate information provided to the advocate; and

- the ability to act on behalf of the resident's interests and preferences throughout the decision-making process.

Kayser-Jones and Kapp (1989) review several possible advocates, noting that each offers advantages and disadvantages and that a different one or a combination may be most appropriate in each case.

The least controversial advocate would be someone named by the resident while he or she is still mentally competent, with the designation contained in a durable power of attorney for health care or a living will, which usually specifies the treatments a person wishes to receive or forego if he or she becomes irreversibly unconscious or severely mentally impaired. However, this option is seldom available because most residents of long-term care facilities do not prepare such directives.

If no decision-maker has been named in advance by the resident, the next choice usually is a family member. However, an increasing percentage of residents have no family member capable or available to act in this capacity. Where family members are available, they may have conscious or subconscious emotions or financial motivations that conflict with the resident's best interests and preferences.

An office already active within nursing homes (in the case of the source article, a nursing home ombudsman program) could be assigned the advocate function, but its staff may lack the necessary skills and experience to advocate effectively in medical decision-making and the office itself may lack the funding for this role. Also, the mandate and current orientation of the office may be incompatible with the strong pro-resident bias the advocate should maintain.

A court-appointed guardian opens the possibility of judicial involvement in selecting a relevant advocate and ongoing oversight of the advocate's activities. The possibility of extensive court involvement, expense, time commitment and increased strain on the parties involved raise potential problems with this approach. Again, such guardians require certain skills and experience and would need guidelines for their actions indicating, for example, whether they should act in a manner consistent with the resident's best interest, spoken choice, or always in favour of maximum medical treatment.

The choice between a stranger or a family member or friend to serve as guardian (or as an advocate under any other arrangement) is difficult and neither is ideal. While a stranger with no emotional involvement with the resident may not make decisions in the resident's best interest, family or friends may be biased by a negative relationship with the resident or may have a financial conflict of interest.

Internal resident representative programs could be created within the organizational structure of the long-term care facility, funded by the facility and supported by its staff, with ready access to residents and staff. A conflict of interest arises in having an advocate paid by the facility and arrangements to overcome conflicts likely would leave lingering questions about the independence of the advocate. Skilled candidates for the position could be difficult to locate and would further increase the bureaucracy of the health care system. Also, funding of the advocate could reduce budgets available for resident care.

Use of volunteers offers the advantages of low cost and access to a pool of compassionate and articulate advocates. However, they would require training and careful screening to safeguard against extreme positions and to ensure the orientation of the advocate is in sympathy with any known interests and apparent best wishes of the resident.

Many staff act as the resident's ally, particularly when there is no family member, and develop knowledge of the resident's wishes through the care relationship. However, serious conflicts of interest can arise between the resident's preference (or one that can be reasonably surmised) and the medical judgment of the practitioner, the written or unwritten policies of the facility, the moral or religious beliefs of staff, and the cost implications for the facility for pursuing certain actions. Also, staff may be biased in their approach to residents they view as a burden or as undesirable.

Kayser-Jones and Kapp (1989) did not endorse any one approach above the others, but recommended that future efforts in this area be guided by several fundamental precepts. First, residents should be encouraged to engage in self-advocacy to the extent possible; when such efforts are supplemented by family, staff and others, they can enhance resident dignity and autonomy. Residents who are able to do so should also be encouraged by families and health practitioners to name their preferred advocate in acute medical decision-making before the need arises.

Whoever serves as the resident's advocate should inform themselves of the resident's wishes and quality of life from those who know the resident well, including the nursing aid who provides most of the daily care. Advocates also need informative and compassionate education to help them fulfil their responsibilities, drawing on such groups as medical and legal societies, nursing organizations, social services agencies, and agencies concerned with aging and the elderly. The lawyers, counsellors, clergy and health care professionals who work with the advocate could also benefit from such training.

Finally, any agency assigned the responsibility for advocacy should be adequately funded, with such funding not drawn from budgets now allocated for resident care.

Appendix A
Methods Used in the Literature Review

This appendix describes the methods used in the literature review, with particular reference to the search for research studies of current practice in the care of the elderly in institutions. Such studies were sought for their potential contribution to the research design and the development of survey instruments for the survey of Homes for the Aged. At the outset, three activities were undertaken:

- Inquiries to various research funding organizations and research organizations;
- A review of bibliographies and a search of computerized data bases for reports on research projects; and
- Search for fugitive literature.

1.0 Inquiries

The search for comparable research projects entailed inquiries to the following organizations:

- Health and Welfare research administrators responsible for three funding programs;
- Social Sciences and Humanities Research Council of Canada;
- Canada Mortgage and Housing Corporation;
- The Quebec Health Research Fund;
- Centres on Aging in Vancouver, Winnipeg, and Toronto;
- U.S. National Institute on Aging;
- Statistics Canada; and
- The National Advisory Council on Aging.

The persons interviewed during this process are listed in Exhibit 1. Most organizations provided lists of recently-funded research projects that, when reviewed, provided leads to a few current studies relevant to the literature review. The Statistics Canada survey instrument for long-term care facilities and three survey instruments used in Quebec nursing homes were also obtained.

Letters were also sent to the 25 members of the Federal/Provincial/Territorial Sub-Committee on Long Term Care, describing our project and asking whether they or their colleagues had surveyed long-term care facilities or similar topics. Members' responses are summarized in Appendix B.

2.0 Review of Bibliographies

The computerized data bases that were searched included AGELINE, covering various aspects of aging presented in journal articles, books, government documents, dissertations, and conference papers; Health Instruments (HIFF), containing information on questionnaires, interview schedules, rating scales and other instruments used in health, health-related and behavioral sciences; Books in Print, covering books currently published in the United States; and Nursing and Allied Health, covering core nursing journals. Initially, each data base was probed with key word combinations that narrowed the search to between 30 and 50 citations from each base, a manageable number to review. AGELINE appeared to be the most useful source and 180 citations dating back to the early 1980s were subsequently obtained.

A bibliography on Alzheimer's disease from The Gerontology Research Centre at Simon Fraser University and a CMHC bibliography on seniors' housing were also scanned. The reference section at the National Advisory Council on Aging was also searched for Canadian reports that may not be catalogued in computerized data bases, and back issues of several Canadian health journals not included in computerized data bases were also scanned.

3.0 Fugitive Literature

Several documents were recommended by key informants and were obtained if possible. These included Gloria Gutman's survey of six special care units in long-term care facilities in British Columbia, and a Health and Welfare Canada draft document Design Guidelines for Facilities for the

Exhibit 1

Key Informants for Literature Review

Cal Zacharias, Judith Strykman	National Advisory Council on Aging Ottawa
Mona Baumgarten	Community Health Department St. Justine Hospital, Montreal
Everest Theriault	National Welfare Grants Division Social Welfare Research Health and Welfare Canada
Chris O'Shaunessy, Patricia Scotcher	Extramural Research Programs Health and Welfare Canada
Frank Fedyk	Policy, Communications and Information Health and Welfare Canada
Victor Marshall	Centre for Studies of Aging University of Toronto
Margaret Penning	Centre on Aging University of Manitoba
Joan Van Nostrand	Behaviour and Social Research National Institute on Aging U.S. Department of Health and Social Services
Cyril Nair	Health Division Statistics Canada
Dr. Norma Stewart	School of Nursing University of Saskatchewan
Don Johnston	Program Implementation Canada Mortgage and Housing Corporation
Brian Gray	Research Division Canada Mortgage and Housing Corporation
Brendan Rule	Department of Psychology University of Alberta (SSHRCC Grant Recipient)
Lynne MacFadgen	St. Joseph's Health Centre Toronto
Jim Redford	Continuing Care B.C. Ministry of Health

Cognitively Impaired Elderly. The MCSS study manager, Joy King, and Homes for the Aged personnel participating in focus groups and site visits were also extremely useful in providing us with documents.

4.0 Observations

We were surprised at the limited number of studies relevant to the design of our survey instrument that were identified through our key informants and review of the literature. We are unsure whether no surveys comparable to ours have not been undertaken, or whether other surveys have been undertaken but are not highly profiled in the published literature or in academic circles.

We identified two Canadian surveys (and their instruments) comparable to ours in scope, and two others that contributed to client profiles in our survey. This material, together with the other references list in Exhibit 2, provided a solid base for approaching development of the survey instrument.

Exhibit 2

Relevant Projects Identified Through the Literature Search

Bergman, Rebecca et al. 1984. "Staff composition, job perceptions, and work retention of nursing personnel in geriatric institutions." International Journal of Nursing Studies 21:279-293.

> This study describes five related measures: (a) observation of specific units (b) questionnaire regarding policy (c) interview with key geriatric staff (d) questionnaire of nursing staff and leavers; (e) interview with nursing personnel.

Canar, Mary Jo and Joseph Johnson. 1986. "An employee learning needs assessment concerning mental health needs of residents in a long-term care setting." The Journal of Continuing Education in Nursing. 17:5-11.

> An employee learning needs/attitude assessment tool is developed and applied as a basis for planning an in-service education program.

Hepburn, Kenneth et al. 1989. "Institutional care of dementia patients: A state-wide survey of long-term care facilities and special care units." The American Journal of Alzheimer's Care and Related Disorders and Research. March/April:19-23.

> This survey of 438 licensed long-term care facilities was designed to obtain information on dementia patient characteristics, behaviour and care problems, programming, design and training needs. A supplemental survey was included for facilities with special care units to gather information on patient, staff and design issues.

Hyde, Joan. 1989. "The physical environment and the care of Alzheimer's patients: An experiential survey of Massachusetts' Alzheimer's units." The American Journal of Alzheimer's Care and Related Disorders and Research. May/June:36-43.

> Eight facilities caring for Alzheimer's patients were visited and staff were interviewed using a semi-structured instrument to obtain information on program

goals, patient profile and the organization of space and design details, and how these affect the patient's behaviour and experience.

MacFadgen, Lynne. 1987. "Sufferers in the Toronto and Peel regions: Perceptions of service providers." Canadian Journal on Aging. 6:271-281.

The objectives of this survey of 41 long-term care facilities, 15 acute care hospitals, and 30 community services included estimating the proportions of residents with irreversible dementias and describing their characteristics, and inpatient and community resources they use.

Mangen, D. J. and W. A. Peterson, eds. 1984. Research instruments in social gerontology: Vol. 3. Health program evaluation and demography. Minneapolis: University of Minnesota Press.

Scales and other instruments used to assess social climate,, staffing and staff training, patient care and physical aspects of long-term care facilities are summarized.

Weiner, Audrey S. and Jacob Reingold. 1989. "Special care units for dementia: Current practice models." The Journal of Long-Term Care Administration. Spring. 14-19.

All 42 facilities in the United States that had been identified as having special programs for Alzheimer's disease were surveyed to identify program objectives, environmental modifications and support systems, staffing, activities, and staff training.

Appendix B

Responses from Members of the Federal/Provincial/Territorial Sub-Committee on Long Term Care

A letter was sent to each of the 25 members of this committee, which compiles an inventory of services across Canada. The letter described the study of Ontario's Homes for Aged and asked whether the member knew of any comparable surveys or guidelines and policies concerning care practices for residents with dementia in long-term care. Replies were received from members in nine provinces and one territory, plus representatives of the federal government. Although none of these mentioned comparable surveys or policies concerning residents with dementia, several provided information of interest in this area. This information is summarized below.

- The Government of Newfoundland and Labrador, Department of Health, is about to begin a project designed to produce standards for nursing homes.

- The Long Term Care Institutions Branch of Alberta Health is in the process of developing guidelines for institutional support and referral services, and for special care units for residents with mental health problems in long-term care facilities. A patient classification system has been developed during the last four years to provide a means of grouping residents according to their care requirements and to serve as a basis for funding, among other purposes. It is not to be used in care planning.

- The British Columbia Ministry of Health has developed design guidelines for Special Extended Care Units, for residents with behaviour disorders, and is developing guidelines for similar units in Intermediate Care facilities.

- The Manitoba Health Services Commission provides consultants to individual facilities to help them identify and resolve their own needs concerning special care for residents with dementia. Special care resource teams of professionals with training and experience in geriatric care and psychiatry provide consultation, education and support to individual facilities. In addition, two special care units have been established for short-term admissions of behaviourally disturbed residents of long-term care facilities.

- The Ministère de la Santé et des Services sociaux in Quebec has researched services for persons with dementia and is developing psychogeriatric teams on a pilot project basis to serve three regions. The position of the department is to integrate residents with dementia to the extent possible.

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